

UNDERSTANDING NARRATIVES OF ILLNESS AND CONTAGION AS A STRATEGY
TO PREVENT TUBERCULOSIS AMONG MÉTIS IN SOUTHERN MANITOBA

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DEDICATION

I dedicate this thesis to my grandmother, Gertie Morsette (1924-2003). It is because of you that this research was done and may your strength, resilience and humor always be remembered.

Rest in peace

I would also like to take this opportunity to dedicate this work to those who have struggled or are struggling with TB and their family members. May your stories and experiences never be forgotten.

ABSTRACT

This study examines how historical and contemporary narratives influence perceptions of tuberculosis among the Métis of southwestern Manitoba. Understanding TB, its prevention, transmission and treatment influence how Métis peoples make a choice when confronted with the illness in their community. These understandings can potentially influence behaviours that contribute to the transmission of the disease or cause delays in seeking medical treatment. Data were obtained by using a qualitative approach that involved interviewing five Métis women, all of whom had a close family member diagnosed with TB. The opened-ended interviews, in combination with personal experience, participant observation, and numerous discussions with people who had direct knowledge of TB in the past and present, provide a glimpse into the reality of how TB narratives influence perceptions regarding the illness. The participant's intergenerational narratives and the lack of public health messaging potentially leave Métis vulnerable to contracting TB if exposed. This study identifies two primary concerns which need addressing in order to prevent TB from reemerging among the Métis in the southwest region of Manitoba: 1) TB education is essential to correct the misconceptions and misunderstandings expressed through historical and contemporary TB narratives; and 2) the continuing consequences of colonialism, such as poverty and poor health that contribute to TB transmission, need to be acknowledged and rectified.

LIST OF ABBREVIATIONS

CDCB	Communicable Disease Control Branch of Manitoba
CLA	Canadian Lung Association
H1N1	Hemagglutinin Type 1 & Neuraminidase Type 1
HIV	Human Immunodeficiency Virus
LTBI	Latent Tuberculosis
MMF	Manitoba Métis Federation
MMF – SWR	Manitoba Métis Federation Southwest Region
Pneumo	Pneumothorax
RRS	Red River Settlement
SDOH	Social Determinants of Health
SWM	Southwest Manitoba
TB	Tuberculosis
TST	Tuberculin Skin Test
WHO	World Health Organization

CHAPTER 1 INTRODUCTION

Colonization¹ is the primary reason as to why rates of tuberculosis have continually been elevated among the Aboriginal peoples of Canada compared to the general population. While public health strategies acknowledge the impacts of colonization, such as social and economic marginalization, little attention, if any, has been paid to the illness/contagion narratives of Métis people. Specifically, health programs that deal with the Métis people have ignored their unique attitudes and circumstances, particularly those having a close family member or friend with TB, or through their own diagnosis and treatment of TB. This thesis examines Métis understandings of how TB is transmitted, the stigma associated with having TB, and local understandings of prevention and treatment. It is argued that these disease-related factors influence how people make choices when confronted with the illness in their community. In turn, these not only influence behaviours that contribute to the spread of the disease, but also affect how those with the TB will be treated.

Illness and contagion narratives of those who have been personally affected by TB or have had close contact with the illness are important for understanding how individuals and communities respond to public health interventions. These narratives are grounded in individual and collective understandings from the past and present. Evidence that helped shape this research included hearing numerous stories by Métis individuals who were sent to the Ninette Sanatorium in the first half of the twentieth century. Their narratives illustrate a strong belief

¹ Colonization is "...some form of invasion, dispossession and subjugation of a peoples. The invasion need not to be military; it can begin-or continue-as geographical intrusion as in the form of agricultural, urban or industrial encroachments. The result of such incursion is the dispossession of vast amounts of lands from the original inhabitants....The long term result of such massive dispossession is institutionalized inequality. The colonizer/colonized relationship is by nature an unequal one that benefits the colonizer at the expense of the colonized." Emma LaRocque, "Colonization and Racism," <http://www3.onf.ca/enclasse/doclens/visau/index.php?mode=theme&language=english&theme=30662&film=16933&excerpt=612109&submode=about&expmode=2> (accessed August 12, 2012).

that if their TB became active again they would be sent back to the sanatorium for treatment. Other individuals, such as family members of patients, described their own fears of the sanatorium, including the fear they would contract TB and be sent away to the sanatorium or that their family member would never return from treatment. By systematically understanding how historical and contemporary illness narratives are constructed, existing misconceptions and misunderstandings can be identified and addressed, which in turn could contribute to a more robust understanding of lay views of TB transmission among the Métis. The goal of this thesis is to begin this process through a preliminary historically based study of Métis perceptions and responses to TB. The findings can inform health care workers, policy makers and other decision makers, including Métis health care leaders, about possible avenues for the reduction of fear and stigma associated with TB and assist in preventing future cases from occurring.

DEFINING THE MÉTIS

Three distinct terms are discussed in this paper, which are the Métis, First Nations² and Aboriginal peoples³. The Métis are descendents of the relationships between European men and Indigenous women that occurred during the fur trade (approximately 1600 – 1850). Historically, the Métis were also known as half-breeds, black Scots, country-born, *Michif*, *bois brûlé*, Chicot or mixed bloods, depending on the ethnic makeup of their ancestors.⁴ The mixed heritage of the

² First Nations peoples are recognized as an “Indian” by the Indian Act. Individuals recognized under this Act automatically fall under federal jurisdiction in areas such as health. Colonial practices have resulted with First Nations peoples being socially and economically marginalized from mainstream society.

³ Aboriginal peoples are those recognized in Section 35(1) of the Canadian Constitution Act, 1982, including Indians (First Nations), Métis, and the Inuit.

⁴ The Canadian Encyclopedia, “Métis,” <http://www.thecanadianencyclopedia.com/articles/metis> (June 21, 2012); Métis Nation of Alberta, “Who are the Métis?” <http://www.albertametis.com/MNAHome/MNA2/MNA-Who2.aspx> (accessed June 21, 2012).

Métis led to the development of a unique language⁵ and culture that combines aspects of Indigenous and European culture.⁶

Consistently throughout history, the Métis have been forced to struggle with colonial powers for official recognition of their personal and collective rights. For example, in 1814 Red River Settlement Governor Miles MacDonnell banned the export of pemmican and prohibited the running of the buffalo, both of which were vital to the Métis economy.⁷ Colonial policies and interventions such as this, led to the formation of *la nouvelle nation* - a new nation, the Métis nation,⁸ as a means to counter government control and oppression. Although the Métis did develop a sense of nationhood from which political and social alliances were built to fight for their right to land and resources, colonial forces were relentless and effective in pushing them to the margins of Canadian society.

The Métis have been socially and economically marginalized throughout Canadian history. However, by the late 19th century their Aboriginal rights were recognized by the Canadian State on two separate occasions: the Manitoba Act (1870) and the Dominion Lands Act (1872). The outcomes of these two Acts prevented Métis rights from securing a more prominent and prosperous place for the Métis in Canada, rather, through treacherous processes on the part of the government and settlers, the Métis lost both their land and economical base. By late

⁵ The language of the Métis is known as Michif. It is generally a mixture of Cree or Ojibway and French.

⁶ Métis Nation of Alberta, "Who are the Métis?" <http://www.albertametis.com/MNAHome/MNA2/MNA-Who2.aspx> (accessed June 21, 2012).

⁷ Yale Belanger, *Ways of Knowing: An Introduction to Native Studies in Canada* (Toronto, ON: Nelson Education Ltd., 2010), 134-5; James S. Frideres and Rene R. Gadaz, *Aboriginal Peoples in Canada*, 9th ed. (Toronto, ON: Pearson Canada Inc., 2012), 250.

⁸ Belanger, *Ways of Knowing*, 134.

1800s, the Métis were virtually invisible, with many residing on road allowances⁹ in tarpaper shacks.¹⁰

The 1960s brought about numerous changes among the Métis. A new sense of pride and unity developed among them reaffirming, "...who they were and where they came from."¹¹ Numerous Métis organizations began to emerge across Western Canada, such as the Manitoba Métis Federation in 1967.¹² This new found sense of nationhood among the Métis resulted in "...the explicit recognition of the Métis as one of the three distinct Aboriginal peoples,"¹³ in the Canadian Constitution Act, 1982. Today, each of the Western Provinces from British Columbia to Ontario has an organization to represent the Métis on a provincial level.¹⁴ Although represented by a number of political organizations and recognized in the Canadian Constitution the Métis continue to struggle for recognition of their rights while simultaneously trying to overcome the ongoing effects of colonial oppression and marginalization.

SYNOPSIS OF THE CHAPTERS

This paper is written as much as possible from past to present, similar to the flow of a narrative. Chapter two is an examination of the fundamentals of tuberculosis, such as how it is spread, diagnosed and treated. Also included within this chapter is a discussion of the social determinants of health and their relationship to the risk factors of TB.

⁹ Once the Métis were dislocated from their lands, many had no options but to reside on road allowances. Road allowances are lands owned by the Crown that run parallel to existing roads for possible expansion or the lands are being held for future roads.

¹⁰ Encyclopedia of Saskatchewan, "Métis Communities," http://esask.uregina.ca/entry/metis_communities.html (accessed May 14, 2012); Todd Paquin and Patrick Young, "Traditional Métis Housing and Shelter," <http://www.metismuseum.ca/media/document.php/00720.pdf> (accessed May 14, 2012).

¹¹ Fred J. Shore, "The Emergence of the Métis Nation in Manitoba," in *Métis Legacy*, eds. Lawrence J. Barkwell, Leah Dorian, and Darren R. PreFontaine, 78.

¹² Shore, "The Emergence of the Métis Nation in Manitoba," 78.

¹³ Métis National Council, "What is the MNC?" <http://www.metisnation.ca/index.php/who-are-the-metis/mnc> (accessed June 21, 2012).

¹⁴ Provincial organizations include: the Métis Nation of British Columbia, Métis Nation of Alberta, Métis Nation Saskatchewan, Manitoba Métis Federation, and the Métis Nation of Ontario. The Métis National Council represents the Métis on the federal level.

Chapter three explores how colonialism impacted the lives of the Métis by providing a historical overview of how the Métis became socially and economically marginalized. Also discussed are the historical perceptions of scholars and physicians as to why TB was persistent among Aboriginal peoples in the late 1800s and early 1900s.

Chapter four reviews the historical literature pertaining to the sanatorium era in Manitoba, such as why sanatoriums were constructed, what it was like to be a patient, and the early treatments provided to TB patients. Other topics examined include the influence of narratives, misconceptions and stigma associated to TB, as well as poverty and inequalities.

Chapter five discusses narrative inquiry, the research method used for this study. This section provides information about the recruitment process; how the research was compiled, transcribed and analyzed; and ethics and confidentiality. In addition, I also provide my own narrative within this chapter, which is intended to help the reader understand my position beyond that of the researcher within the work.

Chapter six is centered on the participant's narratives and the themes that emerged, which include: the sanatorium experience, stigma, misconceptions and misunderstandings, fear of the disease, education, and what the participants think needs be done to stop the spread of TB. Also, a discussion of the findings relating to each theme is provided.

Chapter seven provides recommendations as to what areas need to be addressed. Recommendations include: 1) public health education, 2) addressing lay fears associated with TB as a way to reduce stigma and misconceptions, 3) "decolonization"¹⁵ to address the ongoing social marginalization of Métis and other Indigenous peoples of Canada, and, 4) recognition by

¹⁵ Decolonization involves social and political processes that result in, "...revealing and dismantling colonialist power in all its forms. This includes dismantling the hidden aspects of those institutional and cultural forces that had maintained the colonialist power and that remain even after political independence is achieved." Bill Ashcroft, Gareth Griffiths, and Helen Tiffin, *Post-Colonial Studies: The Key Concept* (London: Routledge, 2000), 63.

government health care decision makers that the Métis are a distinct cultural group, with strong local and regional histories and identities that influence how Métis conceptualize illness and disease, prevention and treatment.

CHAPTER 2

TUBERCULOSIS FUNDAMENTALS

In comparison to other infectious diseases such as HIV, infection rates of tuberculosis are not widely publicized nor do they generate political or public concern despite a new infection occurring approximately every six hours in Canada.¹⁶ The World Health Organization [WHO] reported there were, "...9.4 million new TB cases [worldwide]... in 2009,"¹⁷ and during 2005, approximately one-third of the world's population was infected with the germs responsible for causing TB.¹⁸ In Canada, TB rates of new infections and re-infections were relatively stable between 2000-2010, with the peak being 5.6 cases per 100 000 in 2000 and a low of 4.6 in 2010 for the overall population. However, closer examination of the figures reveals that rates among Aboriginal peoples are much higher. For example, new and re-infection rates in 2010 among Status Indians¹⁹ was 21.8 per 100 000, 116 per 100 000 among the Inuit and 26 per 100 000 among the Métis.²⁰ In order to understand what TB is and why it remains problematic for Canada's Aboriginal peoples, an understanding of the dynamics of the disease, such as what TB is, how it is spread, diagnosed, protocols for reporting cases, treatment, and what behaviours²¹ influence transmission, is needed.

¹⁶ Michelle Phypers, "The Canadian TB Picture," Paper presented at the 6th TB Conference: It's a Small World, Edmonton, AB, March 2008.

¹⁷ World Health Organization. *2010/2011 Tuberculosis Global Facts* (Geneva, Switzerland: World Health Organization, 2010), 1.

¹⁸ World Health Organization. *2006 Tuberculosis Facts* (Geneva, Switzerland: World Health Organization, 2006); Department of Health and Human Services et al, *Guide for Primary Health Care Providers: Targeted Tuberculin Testing and Treatment of Latent Tuberculosis Infection* (Atlanta, GA: Center for Disease Control, 2005), 5.

¹⁹ This figure includes those living on-reserve, off-reserve and unknown residence.

²⁰ Victor Gallant et al. *Tuberculosis in Canada 2010 – Pre-Release* (Ottawa, ON: Minister of Public Works and Government Services Canada, 2012), 6-7.

²¹ Behaviours such as smoking and consuming alcohol increase the risk of contracting TB.

TUBERCULOSIS PROGRESSION

Tuberculosis²² is an airborne illness caused by the bacteria *Mycobacterium tuberculosis*. TB has two stages: primary and active.²³ The primary stage of infection occurs when the germs enter a person's body; this happens when an infected person coughs, sneezes or speaks, and the moisture emitted from their mouth evaporates into the air resulting in droplet nuclei.²⁴ The nuclei can remain in the air for hours and in some instances for days²⁵, and can be inhaled by a non-infected person. When the germs enter the body, one of three things occurs, 1) the immune system will kill off the germs, or 2) latent TB [LTBI] occurs, which is a process whereby the body encapsulates the germs making them dormant, or 3) the disease will become active. Those with LTBI are not infectious and will not have any symptoms of the disease, although they do have approximately a 5-10% chance of the disease progressing to the second stage, active TB, if not treated or treated improperly.

When LTBI progresses to active TB, the patient becomes infectious to others and will begin to show signs and symptoms of the disease. Similar to the flu or a cold, the most common symptoms may include one or more of the following: coughing (of at least three weeks in duration), coughing up blood, fever, night sweats, loss of appetite, fatigue, and chest pain.²⁶

²² Other common historical names for TB include consumption, the galloping plague, phthisis, Koch's Disease, and the white plague.

²³ There three types of TB: human, bovine (includes such animals as cattle, deer, bear, raccoons, coyotes, elk), and avian (bird). Typically, human and avian TB strains only affects the species it is associated with, however, bovine TB can be spread to all other mammals including humans via inhalation or ingestion. Michigan Department of Natural Resources, "Bovine Tuberculosis," http://www.michigan.gov/dnr/0,1607,7-153-10370_12150_12220-99064--,00.html (accessed July 29, 2011).

²⁴ Department of Health and Human Services et al, *Guide for Primary Health Care Providers*, 5.

²⁵ World Health Organization, *Guidelines for the Prevention of Tuberculosis in Health Care Facilities in Resource-Limited Settings* (Geneva, Switzerland: World Health Organization, 1999), 13; Public Health in North Carolina, "Tuberculosis Control," <http://www.epi.state.nc.us/epi/gcdc/tb/faq.html> (accessed August 05, 2010).

²⁶ *Merck Manual of Medical Information*, 2nd Home ed., edited by Mark H. Beers (New York, NY: Pocketbooks, 2003), 1020; *Oxford Medical Dictionary*, 4th ed., edited by Elizabeth A. Martin (Oxford: Oxford University Press, 2007), 736; Dick Menzies and Kamran Khan, "Diagnosis of Tuberculosis Infection and Disease" in *Canadian Tuberculosis Standards 6th Edition*, eds. Richard Long and Edward Ellis (Ottawa, ON: Minister of Health), 73.

Although TB typically affects the lungs, in a form known as pulmonary TB; it can travel to other areas of the body such as the brain, organs, eyes, skeletal system, genitals, and skin via the blood stream if left untreated.²⁷ When TB travels to a secondary site, it is known as extra-pulmonary TB.²⁸

TB can result in death. Ellis and colleagues reported, “For the 1,652 cases diagnosed in 2006... 143 (9%) were reported to have died before or during treatment. Of these, TB was reported as the underlying cause of death for 23 cases (16%).”²⁹ Furthermore, “...124 (8%) of the 1,548 cases diagnosed in 2007 were reported to have died before or during treatment. Of these, TB was reported as the underlying cause of death for 28 cases (23%).”³⁰ Although effective treatments are available to cure TB and death rates are relatively low, death can occur even with treatment. In addition, TB death rates are highly dependent upon the underlying health of the individual and may be exacerbated by coincidental infection with other diseases, notably AIDS.

DIAGNOSING TB

When an individual is suspected of being infected with TB, a Tuberculin Skin Test [TST] is performed. This test involves injecting, “...some testing material under the surface of your skin. If you are infected with TB, the spot where the needle was injected will swell up a bit and feel hard within 48 to 72 hours. Two or three days after the test, you must go back to have your reaction measured.”³¹ If the results are negative, no further testing is typically done unless the

²⁶ Public Health Agency of Canada, “Diagnosing Latent TB Infection,” <http://www.phac-aspc.gc.ca/tbpc-latb/fafi/latenttb-eng.php> (accessed July 31, 2011).

²⁷ Humans can also contract TB by consuming meat or milk infected with bovine TB. Sandoz, “Extra Pulmonary TB,” http://tbdots.com/site/en/doctor_section_tb_extra_pulmonary.html (accessed July 25, 2012).

²⁸ *Merck Manual of Medical Information*, 1020; *Oxford Medical Dictionary*, 736.

²⁹ Edward Ellis et al, *Tuberculosis in Canada 2007* (Ottawa, ON: Public Health Agency of Canada, 2009), 18.

³⁰ Ibid.

³¹ Public Health Agency of Canada, “Diagnosing Latent TB Infection.”

doctor still suspects the patient has TB.³² If the test result is positive, testing for active TB will take place, which involves collecting a sputum sample, a chest x-ray, and the patient's medical history.³³

PROTOCOL FOR CONFIRMED CASES OF PULMONARY TB IN MANITOBA

Once testing is complete and an active case of pulmonary TB is confirmed³⁴, the attending physician and laboratory are required to report the findings to Manitoba Health who then forward the information to the Public Health Agency of Canada. In addition to reporting the confirmed case, a number of other steps will begin simultaneously, including implementing a treatment plan, estimating how long the patient has been infectious; an investigation of the locations the patient has frequented since their symptoms began, as well as who they were in contact with. Establishing how long the patient has been infectious is important because it assists in determining what locations and individuals will be involved in the investigation to trace potential contacts. For example, if it is determined the patient has been infectious for approximately a month, the patient is asked to provide a list of all places they have frequented during this time, and describe the characteristics of each location such as the "...size, ventilation, and length of time spent there."³⁵ This assists in estimating the risk of transmission.

In order to track person to person transmission, newly diagnosed TB patients are asked the names of individuals that they were in contact with at specific locations and when possible provide contact information for these individuals. This process is done for two primary reasons:

1) to identify if any of the contacts have active TB and if so, begin treatment, and 2) to identify

³² A combination of testing is required to ensure an accurate diagnosis. In the event the patient has extra-pulmonary TB additional laboratory testing will be required.

³³ Public Health Agency of Canada, "Diagnosing active TB disease," <http://www.phac-aspc.gc.ca/tbpc-latb/fa-fi/activtb-eng.php> (accessed July 31, 2011).

³⁴ I am only discussing pulmonary TB in this section since it is the most common form of TB.

³⁵ Manitoba Health, Communicable Disease Control Branch, *Tuberculosis (TB) Protocol* (Winnipeg, MB: Government of Manitoba, 2009), 9.

those infected with latent TB and offer treatment to prevent active TB.³⁶ In addition, by contacting individuals the patient has been in contact with, health care providers can sometimes find the original source of the outbreak. The patient's contacts are categorized by the amount of contact they had with the patient and prioritized from close to casual contact.³⁷ Those who have had close contact, such as household contacts, are at higher risk than those who only had casual or limited contact with the infected person. The identified individuals are contacted by a public health care worker, based upon where they are on the priority list, to "...assess the overall health of the contact, administer a TST [TB skin test]...and [if required] schedule [a] further evaluation."³⁸ If an active case is found and confirmed, a contact investigation begins again with the new patient.

EDUCATION

In Manitoba when a person is diagnosed with active TB or LTBI, the physician should provide education to the individual.³⁹ The information is best presented in a clear and concise message that the patient can understand. The information given to the patient should cover the basics of the disease such symptoms, treatment, diagnosis, prevention and outcomes. The physician should also ask the patient if they have any knowledge about the disease, in order to clear up any misconceptions.⁴⁰ Although Manitoba's *Tuberculosis (TB) Protocol* discusses the importance of educating TB patients, there is no mention of education being offered to family members or the patient's community. This lack of information sharing could potentially result in

³⁶ Manitoba Health, Communicable Disease Control Branch, *Tuberculosis (TB) Protocol*, 9, 11.

³⁷ Ibid., 76-7.

³⁸ Ibid., 82.

³⁹ It is not mandatory that physicians in Manitoba provided education to those with diagnosed with active TB. I did ask my family physician in Brandon if she provides education her patients with active TB. She said if an individual already has contracted TB, it is too late to provide education.

⁴⁰ Manitoba Health, Communicable Disease Control Branch. *Tuberculosis (TB) Protocol*, 124-126.

close contacts of the infected person not knowing how to protect themselves or persons in their care, such as children or the elderly.

TREATMENT

Although individuals with latent TB are not infectious, treatment is required to prevent the development of active TB. Treatment involves taking the medication, Isoniazid, biweekly for approximately nine months.⁴¹ During the treatment process, patients should visit their practitioner for general checkups to make certain the medication is working, as well as to ensure the disease has not advanced to the active stage.⁴²

Individuals with active TB are infectious⁴³ and upon confirmation of a positive diagnosis, treatment should begin immediately.⁴⁴ Treatment of active TB is divided into two phases: the intensive phase, which is followed by the continuation phase. The intensive phase involves using a combination of various medications to rapidly kill off the TB germs and to prevent drug resistance⁴⁵ from developing. This phase can take anywhere from one to two months depending

⁴¹ Public Health Agency of Canada, "Treatment of Latent TB Infection," http://www.phac-aspc.gc.ca/tbpc-latb/fafi/treat_tbl-eng.php (accessed August 01, 2011); Vernon H. Hoepfner, Heather Ward and Kevin Elwood, "Treatment of Tuberculosis Disease and Infection," in *Canadian Tuberculosis Standards 6th Edition*, eds. Richard Long and Edward Ellis (Ottawa, ON: Minister of Health), 130.

⁴² International Union against Tuberculosis Committee on Prophylaxis, "Targeted Tuberculin Testing and Treatment of Latent Tuberculosis Infection," <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr4906a1.htm> (accessed July 31, 2011).

⁴³ Some patients may no longer be infectious after two weeks of treatment. This typically depends on what strain of TB they are infected with. D. Ahmad and W.K.C. Morgan, "How long are Patients Infectious?" *Canadian Medical Association Journal* 163.2 (July 25, 2000), 157.

⁴⁴ Some patients may be placed under quarantine or instructed to wear a mask during this time to prevent additional infections from occurring. Typically, a person who adheres to the drug regimen will no longer be infectious after three weeks of starting the medication. Once they are no longer infectious, they will not be required to wear a mask or remain under quarantine.

⁴⁵ Patient adherence is of upmost importance in the treatment of TB. Failure to comply can result in the development of either multidrug-resistance [MDR-TB] or extensive drug-resistant TB [XDR-TB], both of which do not respond to the common medications used to treat the disease. And, not only is treatment of both more expensive, it can also take upwards of two years to treat a single case of either type. Non-adherence is not the only method of acquiring MDR-TB or XDR-TB, those infected with these strains can cause transmission via the same route as active TB. For example, if a person has XDR-TB and is infectious and coughs or sneezes, anyone who is in close proximity may become infected with the XDR-TB strain. Thus, it is vital patients are educated about the importance of adherence not only to ensure the best outcome, but also to avoid the disease from becoming drug

on which combination of medication is used.⁴⁶ The next phase involves the continuation of drug treatment to, “...eliminates the remaining bacteria and prevents subsequent relapse.”⁴⁷ Over and above the time required to complete the intensive phase, the continuation phase can take anywhere from four to eight months depending on which drug regimen is prescribed.

RISK FACTORS

A number of things increase a person’s risk of contracting TB, almost all of which can be linked to an individual’s socioeconomic status. TB risk factors include: poverty, living in overcrowded conditions, close contact with an infected person, malnutrition, homelessness, substance abuse (alcohol or drug), being incarcerated, a weakened immune system, underlying medical conditions such as diabetes and HIV/AIDS, prior TB infection or residing in a community with cases of active TB.⁴⁸ In order to understand why the Métis and other Aboriginal peoples are at increased risk of contracting TB, the relationship between TB risk factors and the social determinants of health [SDOH] needs to be explored. SDOH are the things experienced by an individual in everyday life that can partly determine if they will be healthy or unhealthy, such as education; income and employment; cultural beliefs about illness, disease and contagion; personal health practices; and access to health care services.⁴⁹

resistant. World Health Organization, “World Health Organization Reports Highest Rate of Drug-Resistant Tuberculosis to Date,” http://www.who.int/tb/features_archive/drsreport_launch_26feb08/en/index.html (accessed August 01, 2011).

⁴⁶ Hoepfner, Ward and Elwood, “Treatment of Tuberculosis Disease and Infection,” 117-8.

⁴⁷ Ibid., 117.

⁴⁸ Public Health Agency of Canada. “Tuberculosis Fact Sheets.” http://www.phac-aspc.gc.ca/tbpc-latb/fa-fi/tb_can-eng.php (accessed June 19, 2011); Canadian Lung Association. “Tuberculosis”. http://www.lung.ca/diseases-maladies/tuberculosis-tuberculose/what-quoi/index_e.php (accessed June 19, 2011); Orr, Pamela et al., “Tuberculosis Control in First Nations and Inuit Populations,” in *Canadian Standards, 6th Edition*, eds. Richard Long and Edward Ellis, (Canada: Minister of Health, 2007), 301-02.

⁴⁹ Dennis Raphael, “Introduction to the Social Determinants of Health,” in *Social Determinants of Health: Canadian Perspectives*, ed. Dennis Raphael (Toronto, ON: Canadian Scholars’ Press Inc., 2004), 1; Public Health Agency of Canada, “What Determines Health?” www.phac-aspc.gc.ca/ph-sp/determinants/indexj-eng.php (accessed April 30, 2012).

Those who are disadvantaged in education and employment, such as are many Métis, are more likely to experience the risk factors of TB. In the southwest region of Manitoba [SWM], high school completion rates among the Métis are lower compared to their non-Métis counterparts. For example, in Brandon, Manitoba only 41% of Métis students will complete high school compared to 75% of non-Métis pupils.⁵⁰ Education is directly connected to economic opportunities, for example those with higher levels of education are more likely to be employed. Although, limited information is available in regard to employment rates among Métis, Martens and colleagues found double the amount of Métis children in Brandon reside in homes receiving social assistance compared to their non-Métis counterparts, 31% versus 15.5% respectfully.⁵¹ In addition, for those aged 18 and 19 years old, approximately 19% of Métis youth received social assistance compared to 10.4% of other Brandon youths.⁵² There does seem to be a correlation between high school completion rates and the elevated rates of social assistance among the Métis residing in Brandon, Manitoba.

The increase rates of social assistance⁵³ among the Métis in SWM can negatively impact their health and increase their risk of contracting TB. For example, diabetes⁵⁴, a chronic disease and a TB risk factor⁵⁵, generally affects the poor disproportionately because they cannot afford

⁵⁰ Martens et al, *Profile of Métis Health Status and Healthcare Utilization in Manitoba: A Population-Based Study*, (Winnipeg, MB: Manitoba Centre for Health Policy, June 2010), 601.

⁵¹ Ibid., 602.

⁵² Ibid.

⁵³ During 2011, adults with no dependents collecting social assistance receive \$576.00 per month. Government of Manitoba, "Employment and Income Assistance for the General Assistance Category," http://www.gov.mb.ca/fs/assistance/pubs/eia_general.pdf (accessed June 22, 2012).

⁵⁴ Diabetes is a chronic disease that affects how the body processes sugar. Canadian Diabetes Association, "Diabetes Facts," <http://www.diabetes.ca/diabetes-and-you/what/facts/> (accessed June 21, 2012).

⁵⁵ Catherine R. Stevenson et al, "Diabetes and tuberculosis: the impact of diabetes epidemic on tuberculosis incidence," *BCM Public Health* 7.234 (September 06, 2007) <http://www.biomedcentral.com/content/pdf/1471-2458-7-234.pdf> (accessed June 21, 2012); Blanca I. Restrepo et al, "Cross-sectional assessment reveals high diabetes prevalence among newly-diagnosed tuberculosis patients," *World Health Organization*, <http://www.who.int/bulletin/volumes/89/5/10-085738/en/index.html> (accessed June 21, 2012).

nutritious foods.⁵⁶ Among the Métis in SWM, rates of diabetes are elevated compared to the general population, 10.7% versus 8.8% respectfully.⁵⁷ Not only does poverty result in the inability to purchase nutritional foods, it also increases the risk of developing chronic diseases such as diabetes and can result in a weakened immune system, both of which increase the risk of contracting TB.

An individual's personal behaviours do affect health and influence the risk of contracting TB. During 2006, the Office of the Correctional Investigator stated that Aboriginal peoples accounted for only 2.7% of the Canadian adult population but they accounted for 18.5%⁵⁸ of the federal inmates across Canada; a social context where TB rates have been elevated for years. Another personal behaviour that increases the risk of contracting TB is cigarette smoking.⁵⁹ In 2010, it was reported that the Métis residing in Brandon were more likely to be current smokers compared to the non-Métis, 35.7% versus 23.6% respectively.⁶⁰ In addition to smoking, Martens and colleagues found the Métis consume alcohol more frequently and in greater amounts. Of those consuming five or more drinks at one time, 43.6% of the Métis residing in Brandon reported this type of behaviour compared to 23.4% of the non-Métis population.⁶¹

Long term sustainable solutions are required to improve the overall health of the Métis and reduce their risk of contracting TB. However, in order to effectively address the current

⁵⁶ Andrea Janus, "Poverty a leading cause of Type 2 diabetes, studies say," *CTV News*, November 21, 2010, <http://www.ctv.ca/CTVNews/Canada/20101119/poverty-diabetes-101121/> (accessed June 21, 2012).

⁵⁷ Martens et al, *Profile of Métis Health*, 567.

⁵⁸ When the 18.5% is broken down, First Nations represented 68% of the federally incarcerated inmates, 28% were Métis, and 4% were Inuit. Statistics Canada, "Aboriginal and non-Aboriginal people." Office of the Correctional Investigator, "Backgrounder: Aboriginal Inmates," <http://www.oci-bec.gc.ca/rpt/annrpt/annrpt20052006info-eng.aspx> (accessed May 20, 2012).

⁵⁹ World Health Organization, "Communicable Diseases Department: TB and Smoking," http://www.searo.who.int/en/Section10/Section2097/Section2106_10682.htm (accessed June 27, 2012).

⁶⁰ Martens et al, *Profile of Métis Health*, 597.

⁶¹ Ibid.

problems among the Métis including education and employment the negative ramifications of colonialism need to be addressed and rectified.

SUMMARY

In summary, this chapter has provided a basic explanation of TB, including things such as how it is spread, diagnosed, protocols, treatment and risk factors. Understanding these aspects, specifically the risk factors, are important for understanding why TB remains persistent among the Métis population. Over a century ago Osler said, “Tuberculosis is a social disease with a medical aspect,”⁶² which is still relevant when examining the contemporary TB burden among Métis and other Aboriginal peoples. When individuals are socially disadvantaged, they are at higher risk of contracting TB. For example, those lacking in the area of education may be unable to find employment, resulting in poverty or in some cases homelessness. As will be illustrated in the following chapters, the underlying reason as to why Métis and other Aboriginal peoples continue to experience higher rates of TB is the result of both the historical and contemporary effects of colonization.

⁶² As cited in Richard Long, “The Canadian Lung Association/Canadian Thoracic Society and tuberculosis prevention and control,” *Canadian Respiratory Journal* 14.7 (October 2007), 427.

CHAPTER 3 COLONIZATION OF THE MÉTIS

A multitude of factors, such as poverty, poor housing, and racism contribute to tuberculosis persisting among the Métis and other Aboriginal peoples of Canada. Endemic health and social problems are not only a product of contemporary socio-political-economic conditions, but are also the result of a long and devastating history of colonization of Canada's Aboriginal peoples. Adams argues that colonialism "...dehumanizes and makes the Aboriginal a dependent object whose fate rests on the fickleness of the colonizing society."⁶³ Further, Whitt explains that colonial practices, "Whether or not it is conscious and intentional...serves to extend the political power, secure the social control, and further the economic profit of the dominant culture."⁶⁴ In Canada, colonial practices have continually caused havoc amongst Aboriginal societies. These practices have not only resulted in the continued manipulation of Aboriginal people's belief systems, consciousness, and thought patterns, it also resulted in the colonizer gaining almost complete control over Aboriginal peoples, "...economically, socially, politically...[and] culturally."⁶⁵

The focus of this chapter is to provide an understanding of how colonization impacted the lives of the Métis. First, a brief explanation will be provided as to how the Métis lost their land base and economic stability. As a result of ongoing discrimination and racism, many Métis had no other option than to live on road allowances, marginalized from the general society.

'Marginalization and the Road Allowance' will further explain how the negative perceptions of the Métis prevented their children from attending school. Also, a discussion of the Métis during

⁶³ Howard Adams, *Tortured People: The Politics of Colonization*, (Penticton, BC: Theytus Books, 1999), 6.

⁶⁴ Laurie Anne Whitt. "Cultural Imperialism and the Marketing of Native America." In *Natives and Academics: Research and Writing of American Indians*, edited by Devon A. Mihesuah, 139-171. University of Nebraska Press, 1998. 140

⁶⁵ Adams, *Tortured People*, 37.

the sanatorium era is provided, such as where they were residing, housing, employment and identity. Lastly, this chapter discusses how some physicians of the early 20th century ignored how colonial practices contributed to the spread of TB among Aboriginal people, arguing instead that the genetic makeup and mental inferiority of Aboriginal peoples was to blame for the disease burden they carried.

LAND LOSS

Métis peoples have been victims of discriminatory and racist practices dating back as far as the fur trade (approximately 1600 – 1850).⁶⁶ Eurocentric views held by Europeans and the two primary fur trading companies, the Hudson Bay Company and the North West Company, utilized racist policies to, “...get the greatest amount of labor for the least possible pay.”⁶⁷ Both companies were, “...organized feudally...and used a hierarchical system of status, privileges and loyalties. There was also racial hierarchy in which the Métis, regardless of qualification, could rise only to a certain level.”⁶⁸ Being unable to advance their positions in the companies, meant that the Métis and other Aboriginal peoples held positions that were, “degrading, menial, and [involved] dangerous tasks.”⁶⁹

In order to justify their mistreatment of the Métis, colonizers tended to focus on the “uncontrollable primitive behaviours” of the Métis, such as their “Native” tendencies which included a nomadic lifestyle, their belief system and their personalities, which often were viewed

⁶⁶ The Canadian Human Rights Commission defines discrimination as, “...differential treatment of an individual or a group of individuals based on a prohibited ground, all forms of harassment, systematic discrimination – a seemingly neutral policy or practice which in fact is discriminatory; and retaliation.” Racism, as defined by the Anti-Defamation League is, “...the belief that a particular race is superior or inferior to another, that the person’s social and moral traits are predetermined by his or her inborn biological characteristics.” Canadian Human Rights Commission, “Overview,” http://www.chrc-ccdp.ca/discrimination/act_actes-eng.aspx (accessed August 27, 2011); Anti-Defamation League, “Racism,” <http://www.adl.org/hate-patrol/racism.asp> (Accessed August 27, 2011)

⁶⁷ Howard Adams. *Prison of Grass: Canada from a Native View* (Calgary, AB: Fifth House Publishers, 1989), 11.

⁶⁸ Maria Campbell cited in Murray Dobbin, *The One-and-a-half Men*, (Regina, SK: Gabriel Dumont Institute, 1981), 19.

⁶⁹ Adams, *Tortured People*, 7.

as hostile or childish.⁷⁰ Brady and Norris⁷¹ argue the negative portrayal of the Métis was “...deliberately presented by the conquerors in order to falsify issues and attempts to present some kind of justification for the treacherous ways in which these original pioneers [the Métis] were treated.”⁷²

To ensure the domination of Métis peoples, the Canadian State exercised military force when necessary. Military force was used during both the Red River Rebellion (1870) and the North-West Rebellion (1885). In each instance, the government wanted more land to further expand the West and refused to acknowledge Métis title to the land. For example, when Canada was negotiating with the Hudson Bay Company to purchase Rupert’s Land, the Métis were excluded from the negotiations even though the transaction would affect Métis lands⁷³, economy and way of life.⁷⁴

The government did acknowledge that the Métis had Aboriginal title to the land. In both the Manitoba Act and the Dominion Lands Act (Saskatchewan), a scrip process was used to extinguish Métis’ land title. The scrip process allowed the Métis, on an individual basis, to extinguish title to their land in exchange for lands or monies. However, the scrip process was not without flaws, which included such things as the government not wanting the Métis to acquire the best land, the scrip process was not implemented immediately, the Métis did not have a say on which lands they would be allotted, and those taking scrip were not protected from

⁷⁰ Marcel Giraud, *The Métis in the Canadian West*, Translated by George Woodcock. Vol. II. II vols. (Alberta: The University of Alberta Press, 1986), 197-9, 202; G.F.G. Stanley, *Manitoba 1870: A Métis Achievement*, 15; Dobbin, *The One-and-a-half Men*. 89-90.

⁷¹ Malcolm Norris and Jim Brady were both Métis activists who struggled for the recognition of their people.

⁷² Dobbin, *The One-and-a-half Men*, 89-90.

⁷³ By the early 1800s, the Métis had established a number of settlements in the vicinity of present day Winnipeg, which became known as the Red River Settlement or Assiniboia.

⁷⁴ D.N. Sprague, *Canada and the Métis, 1869-1885* (Waterloo, ON: Wilfred Laurier University Press, 1988), 20, 33.

unscrupulous land speculators.⁷⁵ As a result, the Métis were left without a land base, no political powers or rights to resources,⁷⁶ all of which contributed to the collapse of the Métis economic base and their means of subsistence.

MARGINALIZATION AND THE ROAD ALLOWANCE

Unlike the Indians who signed treaties with government, the Métis were not offered any provisions concerning health, education, famine relief or special status with the federal government. Consequently, many Métis were forced to become squatters on Crown land and became known as the “road allowance people.” High rates of poverty and disease plagued these new Métis communities.⁷⁷ In 1933, Walton’s examination of the previous year’s medical records from Manitoba, found areas with high concentrations of ‘half-breeds’, such as in unincorporated and rural areas, had rates of TB that were much higher than the provincial average.⁷⁸ In another survey conducted at a Métis community in Saskatchewan during 1942, it was found that many of the Métis children suffered from malnutrition, had insufficient clothing, and had diseases such as TB.⁷⁹ Even as late as the 1950s, poverty remained common among those residing on the road allowance. At Rooster Town, a road allowance community in Winnipeg, upwards of 30 to 50 people were residing in “...two to three room shacks without running water, sewer connections or other services.”⁸⁰

⁷⁵ J.M. Bumstead, *The Red River Rebellion* (Canada: Watson & Dwyer Publishing Ltd., 1996), 242-3; Julia D. Harrison, *Métis* (Vancouver, BC: Douglas & McIntyre Ltd., 1985), 76; Lawrence Barkwell, “Métis Lands, Treaties and Reserves,” <http://www.scribd.com/doc/29295744/Metis-Lands-and-Treaties> (accessed May 03, 2012).

⁷⁶ Dobbin, *The One-and-a-half Men*, 61

⁷⁷ Laurie Barron, *Walking in Indian Moccasins: The Native Policies of Tommy Douglas and the CCF* (Vancouver, BC: UBC Press, 1997), 16.

⁷⁸ Walton, Charles H.A., “A Study of the Racial Incidence of Tuberculosis in the Province of Manitoba,” presented at the Winnipeg Medical Society (April 1934), 190.

⁷⁹ Barron, *Walking in Indian Moccasins*, 19.

⁸⁰ Lawrence Barkwell, “Rooster Town: A Métis Road Allowance Community,” <http://www.scribd.com/doc/29295136/Rooster-Town> (accessed May 03, 2012).

Another negative consequence of living on the road allowance was that the children were often denied the right to attend provincial school because their parents did not pay taxes.⁸¹ Métis children were not kept out of school solely because their parents did not pay taxes; racism was also a factor.⁸² During the 1940s, communities in Saskatchewan used the argument that Métis children would be a health threat to the other children if they were permitted to attend school. Barron argues that even if the parents could provide medical documentation indicating their children were healthy, school administrators could still prevent their children from attending by arguing their living conditions were unacceptable.⁸³ Barron further states Métis children were denied an education for the sole fact they were Métis, not because they were a health risk to others or because of the conditions in which they lived.⁸⁴

For some Métis children, education came in the form of residential school. Residential schools were established in 1867, and were designed to “...remove and isolate [Aboriginal] children from the influence of their homes, families, traditions, and cultures, and to assimilate them into dominant culture.”^{85,86} It was mandatory for Indian children to attend residential schools, but the same rules did not apply to the Métis. However, in the event the schools could not find enough Indian children to attend, Métis children were used to increase the attendance,

⁸¹ Fred J. Shore, “Pamphlet#11 -The Métis: The Forgotten Years 1885-1960,” http://umanitoba.ca/student/asc/media/Pamphlet_11.pdf (accessed May 03, 2012).

⁸² Barron, *Walking in Indian Moccasins*, 23.

⁸³ Ibid.

⁸⁴ Ibid.

⁸⁵ CBC News, “Prime Minister Stephen Harper’s Statement of Apology,” <http://www.cbc.ca/news/canada/story/2008/06/11/pm-statement.html> (accessed September 01, 2011).

⁸⁶ Not only did these so-called education institutions attempt to assimilate Aboriginal peoples, they contributed to increased rates of TB among Aboriginal peoples during the first half of the 1900s. For example, a study by the Department of Indian Affairs in 1939, “...estimated 50% of all residential students were suffering from active tuberculosis,” and the following year another study found, “...that 70% of all Aboriginal children in residential schools reacted positively to tuberculin tests.” Mary-Ellen Kelm, *Colonizing Bodies: Aboriginal Health in British Columbia 1900-50* (Vancouver, BC: UBC Press) 66.

which in turn increased the funding the school received.⁸⁷ Métis children were often subject to racism when attending residential school. Typically Métis children deemed "...orphans or illegitimate,"⁸⁸ or those living like Indians were preferred over those living a more "Westernized" lifestyle.⁸⁹ Therefore, it was more likely that the road allowance children attended residential school.

THE MÉTIS AND THE SANATORIUM ERA

During the sanatorium age in Manitoba (approximately 1910 to the early 1960s) the Métis were virtually invisible.⁹⁰ The majority of middle and lower class⁹¹ Métis had migrated out of the Red River area (present day Winnipeg) by the late 1880s because of disappearing buffalo, the failed scrip system and the influx of settlers and troops. Many relocated to smaller communities in western or northern Manitoba (St. Laurent, St. Lazare, St. Ambroise, Ste. Madeleine, Duck Lake, Turtle Mountains, Portage La Prairie, St. Francois Xavier) or to places such as Saskatchewan, Montana, or North Dakota. Not only did the Métis disperse from their traditional lands, their political strength diminished and their unity as a nation dissolved.

As settlement continued on the prairies, the semi-nomadic life of the Métis was vanishing and being, "...replaced by the way of life of a new society founded in agriculture and industry."⁹² Employment opportunities for the Métis were generally limited to unskilled casual labour positions. Harrison states that most Métis men were employed in temporary in positions

⁸⁷ Tricia Logan, *The Lost Generation: The Silent Métis of the Residential School System* (Manitoba: Southwest Region, Manitoba Métis Federation, 2001), 13.

⁸⁸ Ibid., 22.

⁸⁹ Ibid.

⁹⁰ A gap exists in the literature pertaining to the Métis in Manitoba from approximately 1900 to 1960.

⁹¹ The upper class Métis remained and integrated into general society. Giraud, " *The Métis in the Canadian West*, 469-475.

⁹² Social and Economic Research Office, *A Study of the Population of Indian Ancestry Living in Manitoba*, under the direction of Jean H. Lagasse. Vol. I. IIV vols. (Winnipeg, MB: Department of Agriculture and Immigration, 1959), 53.

such as, "...labouring on threshing crews, digging Seneca root, cutting and hauling wood and, in the more northern areas, hunting and trapping,"⁹³ whereas the women tended to be employed as domestic help with non-Métis families.⁹⁴ In the report, *The People of Indian Ancestry in Manitoba*, by the Department of Agriculture and Immigration (1959) stated that many Métis continued to be employed in unskilled positions, such as farm hands, lumber and pulp workers, and seasonal work such as picking berries and roots.⁹⁵ The lack of permanent employment resulted with many Métis living in poverty and substandard conditions.

As previously discussed, many Métis peoples had no other choice than to become squatters on road allowances or to live in the "...slums on the fringes of Indian reserves and white communities."^{96,97} There were five common types of dwellings among the Métis residing in rural Manitoba during the late 1950s, including: 1) log homes that generally ranged from 20' x 10'; 2) shacks described as, "...one or two room dwellings of a temporary nature and usually poorly and cheaply constructed. They are rarely lined on the inside and tar paper or roofing is often used as siding"⁹⁸; 3) framed homes that were older homes constructed of wood; 4) modern homes which were those similar to contemporary homes, and 5) tents which were generally used as temporary summer homes however, there were cases of Métis living in tents year round.⁹⁹

⁹³ Harrison, *Métis*, 92.

⁹⁴ Ibid.

⁹⁵ Social and Economic Research Office, *A Study of the Population of Indian Ancestry*, vol I, 80-3.

⁹⁶ John Weinstein, *Quiet Revolution West: The Rebirth of Métis Nationalism*, (Calgary, AB: Fifth House Ltd., 2007), 20.

⁹⁷ Some of the Métis settlements located on the outskirts of non-Métis communities in Manitoba include: Melonville, Rooster Town (present day Winnipeg), Smokey Hollow, Bannock Town, Fort Tuyau, Fort Rouge, Little Chicago, Mud Flats, Shaughnessy Heights, Pumpville, Tintown, and La Couleee. Social and Economic Research Office, *A Study of the Population of Indian Ancestry*, vol. I. 68.

⁹⁸ Social and Economic Research Office, *A Study of the Population of Indian Ancestry Living in Manitoba*, under the direction of Jean H. Lagasse. Vol. II. IIV vols. (Winnipeg, MB: Department of Agriculture and Immigration, 1959), 27.

⁹⁹ Ibid, 27-28.

Even as late as the 1950s some Métis continued to reside on the road allowance in areas such as Gladstone and McGregor, both of which are situated in the southwest region of Manitoba.

The Métis also experience identity issues, not only as a nation but also as individuals. St. Onge explains:

When the “Métis” were defined by society at large, some allusion to Indian ancestry was made and physical characteristics were noted...but...these were given social significance only because of the lifestyle led by the individuals. In the 20th century “Métis” came to be synonymous with being poor, unschooled, living in a shack, or engaged in a variety of seasonal employments...Métis [families or individuals that] became prosperous, its white parentage was emphasized.¹⁰⁰

The racist views held by the vast majority of general society and the government in regard to the Métis resulted with some Métis opting to assimilate into Euro-Canadian society, by denying or hiding their Métis ancestry.^{101, 102} It was not until the 1960s that the Métis in Manitoba begun to regain their strength as a nation.

Throughout the sanatorium era, the Métis in Manitoba continued to socially-politically-economically marginalized. Not only did they lose ownership of their traditional lands, they became social outcasts, forced to live on the margins of society. The racist perceptions of the Métis limited their economic opportunities, which in turn affected their living conditions. One method that some Métis used to blend into mainstream society was to assimilate by denying or hiding the fact they were Métis. Although most Métis have regained their identity individually and as a nation, the marginalization they experienced during the sanatorium age has persisted to present day.

¹⁰⁰ Nicole St. Onge, *St. Laurent, Manitoba: Evolving Métis Identities, 1850-1914* (Regina, SK: Canadian Plains Research Centre, 2004), 4.

¹⁰¹ Weinstein, *Quiet Revolution West*, 22.

¹⁰² A good example of a Métis person hiding their ancestry is my grandmother. On her first marriage certificate she listed herself as French. However, on my mother's birth certificate my grandmother listed her ethnicity as Scottish. Seldom would she admit her Métis ancestry.

IGNORANCE OF COLONIAL IMPACTS

Historical evidence indicates that the negative effects of the various assimilation policies and practices, whether directly or indirectly, were responsible for the increased rates of TB among Aboriginal peoples.¹⁰³ Stewart, Medical Superintendent of the Sanatorium Board of Manitoba, alleged poverty was ultimately responsible for the high TB rates. He stated, "...we must remember that the Indian is in the difficult position of having almost lost his own world of the open spaces and their various employments, while he has only small and occasional chances in the white man's world."¹⁰⁴ Ferguson, a pioneer in Canada's fight against TB in the 1900s, posed a similar argument as to why TB was problematic among Aboriginal peoples,

The moral and physical weakening of the Indian has to do with the introduction of the horse...fire-arms...liquor, the exchange of their fur tunics for the blanket, the exchange of the clothes necessary for warmth for alcohol, the extermination of the buffalo and the beaver, the concentration upon reserves, the change of housing, the change of food, the exclusion of sun food by the clothing of the children; the compulsory concentration of children in schools, the change of occupation from hunting and warring to agriculture pursuits, and, on the mental side, the psychical depression of conquest by the whites, dependence on the Government rations for food, visible ravages of white man's diseases, desertion by, or incompetency of, their Michi-Manitou {sic}, and their triumph of Kitchi-Manitou, and the failure of even the white man's religion to protect them.¹⁰⁵

Both Stewart and Ferguson point out that the poverty experienced by Aboriginal peoples resulted because of land loss, collapse of their economic base, all of which were the result of European colonization.

Not all physicians of the early 20th century linked the effects of colonialism to rates of TB transmission. Bell, a physician who conducted a medical survey of the Wabaska District

¹⁰³ Ferguson, *Tuberculosis among the Indians* (London: Allard and Son, Ltd, 1928), 5; David A. Stewart, "The Red Man and the White Plague," *Canadian Medical Association Journal* 36.6 (December 1936): 674; E.L. Ross and A.L. Paine, "A Tuberculosis Survey of Manitoba Indians," *Canadian Medical Association Journal* 41.2 (August 1939), 181; W.W. Bell, "A Report of a Medical Survey in the Wabaska District," *Canadian Medical Association Journal* 12.10 (October 1922): 726

¹⁰⁴ Stewart, "The Red Man and the White Plague," 675.

¹⁰⁵ Ferguson, *Tuberculosis among the Indians*, 31

(Northern Alberta) in 1922, utilized a stereotypical image of Aboriginal peoples to explain why TB persisted:

The chief trouble with the [Aboriginal] people throughout all this district is laziness. The children are allowed to do what they like at all times. There is no discipline: only girls are made to do any work. The result is that when the boys reach manhood they refuse to work except under compulsion and live with their parents, often when they marry bringing their wives back to their parents' small teepee to crowd it still more. Another cause of trouble is a propensity for gambling, and an absolute inability to value money. Added to this is a love for any kind of spirituous liquor.¹⁰⁶

Bell's failure to examine why the poor living and social conditions of Aboriginal peoples existed, directly placed the blame on the Aboriginal population as to why the disease remained problematic.

Many medical professionals of the time, such as Bell, viewed Aboriginal peoples as inferior to Europeans and treated them accordingly. For example, Lux argues that one of the posters designed to warn Aboriginal peoples about TB and how to reduce the risk of infection was, "...a series of simplistic questions and answers 'designed to easily arouse the attention of the more primitive type of Indian mind.'"¹⁰⁷ Not only are the questions simplistic, the statement located at the bottom of the poster is also demeaning. It states,

Don't drink whisky. Whisky and allied drinks are the world's national curse. Don't neglect to call the medical doctor when seriously sick, and, when you do call him, cooperate with him. Don't wear wet moccasins. They may be economical, but they are not healthy. Don't hunt for \$100 a season if you can make \$1,000 by farming. Don't be filthy. Water is free where you live.¹⁰⁸

¹⁰⁶ Bell, "A Report of a Medical Survey," 726.

¹⁰⁷ Maureen Lux, *Medicine that Walks: Diseases, Medicine, and Canadian Plains Native Peoples 1880-1940* (Toronto, ON: University of Toronto Press, 2007), 198.

¹⁰⁸ Ibid.

This poster illustrates how the medical profession assumed Aboriginal peoples were incapable of taking care of themselves and only through conforming to a Western lifestyle, including a wage based-profit economy, their lives could be improved.

Scholars and medical professionals who drew upon the misconceptions about Aboriginal people not only helped to strengthen negative stereotypical images¹⁰⁹ of Aboriginal families and homes, but it allowed the dominant society an avenue to blame Aboriginal peoples for their health disparities. The most common theme to explain TB among Aboriginal peoples held by scholars and medical professionals was the image of the “dirty Indian”. Kelm explains that it was assumed Aboriginal peoples, “...would not ‘adopt civilized methods of sanitation.’ Others seemed to put the blame even deeper in Aboriginal society – it was not that they would not, but that they could not adapt.”¹¹⁰

In addition to claiming Aboriginal peoples were unclean and lived in squalor supported the belief that Aboriginal peoples were genetically inferior¹¹¹ and reinforced the myth that, “...‘primitive races’ were more susceptible to tuberculosis than westerners.”¹¹² However, Hodgson argues that increased susceptibility was not due to “genetic weakness”, but instead to environmental factors.¹¹³ Werrett agrees it was not a genetic predisposition that caused high rates of TB among Aboriginal peoples, but rather,

At the turn of the century mankind was still helpless against tuberculosis, but there were factors in the everyday life of the Indians that made them particularly and devastatingly vulnerable to attack. Epidemiologists have long recognized that

¹⁰⁹ Stereotypes about Aboriginal peoples include such things as dirty, drunks, unable to care for their children, lazy, and stupid.

¹¹⁰ Kelm, *Colonizing Bodies*, 39.

¹¹¹ Julie Cassidy, “The Legacy of Colonialism,” *The American Journal of Comparative Law* 51.2 (Spring 2003): 454; Duncan C. Scott, “The Aboriginal Races,” *Annals of the American Academy of Political and Social Science* 107 (May 1923): 66.

¹¹² Corinne Hodgeson, “The Social and Political Implications of Tuberculosis among Native Canadians,” *Canadian Review of Sociology and Anthropology* 19.4 (November 1982): 506.

¹¹³ *Ibid.*, 506.

people who have had no previous experience with a communicable disease have no built-in immunity to it, and so it was with the Indians and the onslaught of tuberculosis. Added to their lack of immunity was the fact that they lived in crowded teepees and lodges where isolation of the sick was impossible, even if they had recognized the necessity for it. Malnutrition also aggravated the situation.¹¹⁴

It is evident that scholars, members of the medical profession, and government officials who argued Aboriginal peoples were genetically inferior to account for the high rates of TB infection, failed to explore how colonial policies and their impact drove the spread of TB among the Métis and other Aboriginal peoples.

SUMMARY

It is evident the negative effects of colonialism were, and continue to be, directly linked to the elevated rates of TB among Métis and other Aboriginal peoples. The most damaging result of colonialism experienced by the Métis is the loss of their land base in the late 1800s. The loss of their land base resulted in other problems such as the collapse of their economic base (farming), their access to subsistence (hunting, access to traditional medicines, plants and berries), as well as their unity as a nation. As a result, many Métis had no other option except to reside on the road allowance, causing further oppression and destruction. Shore, a Métis historian and professor in the Department of Native Studies at the University of Manitoba, explains that when the Métis relocated to the road allowance and separated from one another it affected them as a 'nation' because their primary concern became their individual families.¹¹⁵

¹¹⁴ George Wherrett, *The Miracle of the Empty Beds: A History of Tuberculosis in Canada* (Toronto, ON: University of Toronto Press, 1997), 99.

¹¹⁵ Shore, "The Emergence of the Métis Nation," 77.

The once economically independent Métis ended up having to collect welfare or work for low wages to survive.¹¹⁶

Compounding the problems created by the loss of land was the fact that Métis children were denied equal access to education because of the racist attitudes held by the general population. Racism not only prevented Métis children from attending public schools, it was also a factor determining which Métis children would attend residential school. The failure to allow Métis children a right to an equal education contributed to the economic and social marginalization of the Métis, which is still evident today. For example, unemployment rates among the Métis in Saskatchewan during April of 2011, were almost triple that of the non-Métis population, 14.8% versus 5% respectfully.¹¹⁷

Not only were Métis peoples marginalized economically and socially from the general society during the 18th and 19th centuries, but they were often blamed for their health disparities because of their perceived mental and genetic inferiority. Not only did some physicians and scholars focus on the stereotypical image of the “dirty” and genetically inferior “Indian”, they also helped to engrain this racist perception of Métis and other Aboriginal peoples among Canadian-European society.

In order to understand the present TB situation among Métis peoples, an understanding of how colonization influenced the lives of Métis families must be recognized and understood. The racist policies and practices of the State resulted in a persistent cycle of despair among Métis: poverty leads to poor health and poor health leads to poverty. Therefore, in order to understand

¹¹⁶ Bruce D. Sealey and Antoine S. Lussier, *The Métis: Canada's Forgotten People* (Winnipeg, MB: Manitoba Métis Federation Press, 1975) 156.

¹¹⁷ Shari Narine, “Saskatchewan Briefs – June,” <http://www.ammsa.com/publications/saskatchewan-sage/saskatchewan-briefs-june> (accessed June 17, 2012).

the contemporary TB situation among Métis peoples of Canada, the negative ramifications of colonization must be included.

CHAPTER 4

UNDERSTANDING THE TOPIC USING EXISTING LITERATURE

In areas of health, there is a body of literature, both contemporary and historical focusing on First Nations and health disparities. However, much less attention has been paid to the health disparities among the Métis. Literature discussing how Métis people perceive tuberculosis historically and as a contemporary disease is non-existent. Métis specific literature generally focuses on historical events such as the Red River Rebellion or the Northwest Rebellion, or on prominent Métis individuals like Louie Riel or Gabriel Dumont,¹¹⁸ rather than on the impacts these events had upon the health of Métis people. Many health researchers today tend to combine First Nations, Métis and the Inuit under the generic term “Aboriginal”.¹¹⁹ However, while each of these groups has been harmed by colonization and as such share similar health disparities, the term “Aboriginal” masks circumstances and health determinants specific to each group. For example, literature examining TB uses the term “Aboriginal” even though the majority of the material is specific to First Nations. As a result, a false representation is created, not only regarding how First Nations experience the disease, but also the Métis and Inuit.

THE SANATORIUM AGE IN MANITOBA

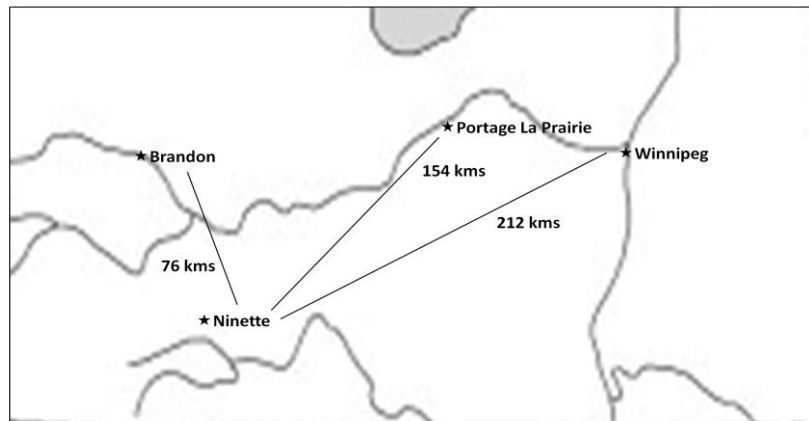
Tuberculosis hit Canada the hardest in the early half of the 20th century. When this occurred little was known about how to prevent and treat the disease. The treatment regimen at the time included: the quarantine of infected individuals, plenty of fresh air, ample bed rest, and good nutrition. Canada opened its first sanatorium in Ontario in 1897, modeled after American

¹¹⁸ Sprague, *Canada and the Métis*; Bumstead, *The Red River Rebellion*.

¹¹⁹ The constitutionally recognized Aboriginal peoples of Canada include First Nations, Métis and the Inuit. In terms of health, the federal government is in control of First Nations and the Inuit people’s health, whereas the Métis are a provincial concern. As a result, there are vast amounts of statistical information available in regards to First Nations and the Inuit. However, statistical information is not recorded by the province based on cultural background, thus there is limited statistical information in regard to Métis healthcare utilization.

and European sanatoriums that were already operating.¹²⁰ It did not take long for the new specialized institutions to expand across the country and in 1938, there were 61 sanatoriums in Canada with close to 9000 beds. By 1953 there were 101 sanatoriums and TB units in general hospitals with a total of 19 000 beds.¹²¹ Although it was thought sanatoriums could provide the “cure”, 45% of patients within the first 25 years of the sanatorium era perished.¹²²

During the latter decades of the 1800s, Manitoba health officials knew that TB was a serious health problem for citizens of the province; however the province did not launch its first anti-tuberculosis campaign until 1904. The campaign was developed when twenty-four prominent Winnipeg residents formed the Sanatorium Board of Manitoba. The goals of the Board were to educate the public about the disease and to establish the first sanatorium within the Prairie Provinces.¹²³



Map of Southern Manitoba: Distances to Ninette Sanatorium

Ninette Sanatorium, located on the shores of Pelican Lake¹²⁴, admitted its first patient on May 20, 1910.¹²⁵ Stewart explained when the Ninette Sanatorium opened, it was, “...to admit only patients with early or minimal disease who would likely be able to return to their families and their work fairly quickly.”¹²⁶

¹²⁰ Saskatchewan Lung Association, “Time Line of TB in Canada,” <http://www.lung.ca/tb/tbhistory/timeline/gage.html> (accessed July 1, 2009).

¹²¹ Stephen Grzybowski and Edward A. Allen, “Tuberculosis: 2. History of the Disease in Canada,” *Canadian Medical Association Journal* 160 (1999): 1026.

¹²² Ibid.

¹²³ Wherrett, *The Miracle of the Empty Beds*, 192; David B. Stewart, *Holy Ground: The Story of Ninette Sanatorium at Ninette* (Killarney, MB: J.A. Victor David Museum Inc.), 1.

¹²⁴ Pelican Lake is located approximately 210 kilometers from Winnipeg, MB.

From 1910 until 1946, a number of other facilities were established in Manitoba for the treatment of TB. Winnipeg was selected for many, which included King Edward Hospital (1912), the Central Tuberculosis Clinic (1930), and the St. Boniface Sanatorium (1931). Others included St. Peters Dynevor (1939-1957) in Selkirk, Clearwater Sanatorium in The Pas (1945-1956), and the Brandon Sanatorium (1946-1958) located in Brandon.

Manitoba had four institutions designated for TB treatment prior to 1935, however only individuals with wealth, "...could afford to enter a sanatorium where they would receive proper care and, if the disease was stopped early enough, perhaps could be cured."¹²⁷ Wherrett explains that those on the opposite end of the monetary spectrum were often left with no viable treatment option because; "Hospital wards closed their doors [to poor TB patients] along with the rest of society."¹²⁸ Because of this, numerous excuses were put forth by funding agencies not to support treatment, such as, "...provincial authorities claimed lack of finances, charities said it was hopeless to attempt a task so big without government help, and municipal and federal governments claimed it was not their responsibility or under their jurisdiction."¹²⁹ The lack of funds for treatment not only resulted in deaths, which may have been prevented with treatment, it contributed in the ongoing spread of the disease.

Despite numerous sanatoriums existing, not all allowed Aboriginal patients. At the peak of the epidemic in 1930s, "...[First Nations and Inuit] patients were rarely offered sanatorium treatment."¹³⁰ For instance, in 1932, 69% of non-Aboriginal TB patients died in a hospital

¹²⁵ Wherrett, *The Miracle of the Empty Beds*, 192.

¹²⁶ Stewart, *Holy Ground*, 13.

¹²⁷ Wherrett, *The Miracle of the Empty Beds*, 12.

¹²⁸ Ibid.

¹²⁹ Ibid.

¹³⁰ Ibid., 1026.

setting compared to 33% of Métis TB patients and 10% of Indians who died at home.¹³¹ The primary reason the government decided to begin to help Aboriginal people afflicted with TB, was that the spread of the disease among Aboriginal peoples meant they were becoming a threat to the general society, a population in which TB rates had already significantly decreased. As explained by Moore, "...it was in the selfish interest of the white man, for his own protection, to take steps to control the tuberculosis in the red man."¹³²

When TB treatment was provided it was not offered equally to the Métis and First Nations. The federal government was responsible for supplying health services to First Nations, whereas, the Métis fell under provincial jurisdiction.¹³³ Waldram, Herring, and Young explain¹³⁴ that in Southern Alberta, First Nation reserves were visited by a team of healthcare professionals (i.e. doctors and nurses), yet Métis who resided in the North rarely received the same attention because of the increased distance. In addition, First Nations in Southern Alberta were offered TB treatment in 1935, whereas this same treatment was not provided for the Métis until the 1940s, again due to the distance and the costs of travelling.¹³⁵ Not only were Métis denied the same treatment as their First Nations counterparts, they were even suspected of exposing First Nations peoples to the disease.¹³⁶

¹³¹ The literature does not indicate exactly where the "Indians" were at the time of their death. However, I assume since they were not in a hospital setting the "Indians" were at home. Walton, Charles H.A., "A Study of the Racial Incidence of Tuberculosis in the Province of Manitoba," presented at the Winnipeg Medical Society (April 1934), 190.

¹³² P.E. Moore, "No Longer Captain: A History of Tuberculosis and its Control amongst Canadian Indians," *Canadian Medical Association Journal* 84.18 (May 06, 1961): 1013.

¹³³ The various provinces remain responsible for Métis healthcare and First Nations health continues to be a federal concern.

¹³⁴ James B. Waldram and Ann D. Herring and T. Kue Young, *Aboriginal Health in Canada: Historical, Cultural, and Epidemiological Perspectives* (Toronto, ON: University of Toronto Press, 2006), 207-8.

¹³⁵ Ibid.

¹³⁶ Lux, *Medicine that Walks*, 207.

LIFE IN THE SANATORIUM

Tuberculosis patients typically spent a minimum of a year in the sanatorium. During this time, some patients who resided close to the sanatoriums had visitors, however depending on how infectious he or she was at the time, a visitor might not have been allowed to have close contact. A patient in the study by Gibson and colleagues, who spent nine months in the sanatorium stated, “It was not a good time for me...I was lonesome for my parents, my mom, the kids, my sisters. I missed them a lot.”¹³⁷ Other patients also reported feeling lonely, “...I was there [the sanatorium] for the longest time. I never came home...I never even received any mail. No mail, no TV. That’s how it was: very lonely.”¹³⁸

Many Aboriginal peoples can recall family members being sent away for treatment and not returning because of losing their battle with the disease. Funk found that, “To this day, adults of communities around Alaska tell tales of loved ones leaving the village to go to the sanatorium; many never returned. Some lost entire families to TB.”¹³⁹ Many Aboriginal peoples still believe those requiring treatment for TB are admitted to a sanatorium because as Jenkins found, some individuals continue to, “have the fear of being sent away for treatment to die.”¹⁴⁰

Another important issue missing from the research is how Aboriginal TB patients were treated in the sanatorium. The Qikiqtani Inuit Commission¹⁴¹ found that some Inuit children

¹³⁷ N. Gibson et al. “Socio-Cultural Factors Influencing Prevention and Treatment in Immigrant and Aboriginal Communities in Canada.” *Social Science and Medicine* 61.5 (September 2005): 938.

¹³⁸ *Ibid.*, 938.

¹³⁹ E.A. Funk, “Tuberculosis control among Alaska Native Peoples,” *Int. Journal of Tubercle and Lung Disease*, 2.9 (1998), S27.

¹⁴⁰ Don Jenkins, “Tuberculosis: The Native Indian Viewpoint on Its Prevention, Diagnosis, and Treatment,” *Preventative Medicine* 6 (1977), 553

¹⁴¹ “The Qikiqtani Truth Commission (QTC) was established by the Qikiqtani Inuit Association (QIA) to create a more accurate and balanced history of the decisions and events that affected Inuit living in the Qikiqtani (formerly Baffin) region in the decades following 1950, and to document the impacts on Inuit life.” Qikiqtani Inuit Association, “Qikiqtani Truth Commission,” <http://www.qtcommission.com/documents/main/QTCFinalReportOctFINAL.html> (accessed February 25, 2012).

who were patients in southern TB sanatoriums were not permitted to speak their native tongue and they were also, "...subjected to disciplinary measures, such as spankings, being hit, force-fed or tied to their beds for hours."¹⁴² The Inuit are not alone in their claims of abuse. Ex-patients of the Clearwater Lake Sanatorium, near The Pas, Manitoba, also recalled episodes of abuse. One former patient recalled, "... [that] most of the children were afraid, because if they stepped out of line, they were beaten with thick, leather belts."¹⁴³ Not only did this man recall physical abuse, he also spoke of emotional and psychological abuse, "...the macaroni...[I] was to eat was something...[I] had never tasted before and after tasting some...[I] threw up on...[my] plate. 'The nurse got really angry and mixed up the macaroni and vomit and force fed it to me.'"¹⁴⁴

HISTORY OF TB TREATMENT

During the early half of the 20th century, treatment options for TB were limited and in many instances not effective. Not only were the treatments ineffective, many were painful and life altering for the patients. When Ninette Sanatorium opened in 1910, the most common treatment at the facility was bed rest, plenty of fresh air, and a healthy diet. Beds were often placed on screened patios, allowing patient's access to as much fresh air possible.

In 1914, a new experimental surgical treatment option, pneumothorax [pneumo], was introduced for patients suffering from pulmonary TB. At the time it was known that TB patients experienced a buildup of fluid in the pleural space, which is the space between the lung and the chest wall. Pneumo involved the insertion of a needle between two ribs and injecting air into the pleural space, which would collapse the lung, allowing it to rest. In addition, while the lung was

¹⁴² Qikiqtani Inuit Association, "Qikiqtani Truth Commission."

¹⁴³ Rob McKinley, "More Canadian Genocide: TB Sanitariums," *Windspeaker News*, September 1998, <http://sisis.nativeweb.org/clark/sep98can.html> (accessed March 02, 2012).

¹⁴⁴ Ibid.

collapsed, any holes that may have been caused by the disease were given a chance to heal.¹⁴⁵

Not all patients were candidates for pneumo, and those who were, typically received the treatment once or twice weekly for the duration of their stay at the sanatorium.¹⁴⁶

By the 1920s, pneumo and bed rest remained as the two most utilized treatments for patients with pulmonary TB. For those suffering from non-pulmonary forms it was thought that heliotherapy, exposure to sunlight, would be beneficial.¹⁴⁷ During the summer, these patients would be placed on cots outside for heliotherapy, which was similar to sun tanning. During the winter months, artificial sunlamps would be used indoors. While heliotherapy initially was thought to be an effective treatment, it was later proven to have no benefit to treat TB.¹⁴⁸

As the 1920s ended, an additional form of collapse therapy was introduced for pulmonary TB patients. Phrenicotomy surgery became an option for those experiencing TB in the lower section of the lung.¹⁴⁹ This surgery involved crushing or dissecting the phrenic nerve, which is responsible for diaphragm function. By severing or crushing the nerve, diaphragm function would cease, allowing less stress on the lung. Temporarily crushing the nerve would last approximately three to six months, and could be performed, and typically was, a number of times. For those patients who had the nerve severed, paralysis of the diaphragm was permanent.¹⁵⁰

¹⁴⁵ Stewart, *Holy Ground*, 20; Saskatchewan Lung Association, "Treatments of Tuberculosis: Artificial Pneumothorax," <http://www.lung.ca/tb/tbhistory/treatment/pneumo.html> (accessed May 02, 2012).

¹⁴⁶ Ibid.

¹⁴⁷ Saskatchewan Lung Association, "Treatments of Tuberculosis: Heliotherapy," <http://www.lung.ca/tb/tbhistory/treatment/heliotherapy.html> (accessed May 02, 2012).

¹⁴⁸ Stewart, *Holy Ground*, 34-5; Saskatchewan Lung Association, "Treatments of Tuberculosis: Heliotherapy."

¹⁴⁹ Stewart, *Holy Ground*, 64.

¹⁵⁰ Saskatchewan Lung Association, "Treatments of Tuberculosis: Phrenic Nerve Crush (Phrenicotomy)," <http://www.lung.ca/tb/tbhistory/treatment/nervecrush.html> (accessed May 02, 2012).

By 1935, Ninette Sanatorium had a new operating room¹⁵¹ and a new surgeon, Dr. Herbert Meltzer.¹⁵² During this time, patients who had no hope of survival could receive thoracoplasty surgery. This form of collapse therapy involved numerous operations, removing two to three ribs per surgery, until approximately 7 to 8 ribs were removed in total.¹⁵³ It was also around this time that local anesthesia was introduced for collapse therapy.¹⁵⁴ Thoracoplasty surgery was used until the 1960s, at which time it was replaced by newer, more effective therapies.¹⁵⁵

For those suffering with TB who were not candidates for pneumo and thoracoplasty, another invasive technique, known as plombage, was used. Patients receiving this treatment would have paraffin wax¹⁵⁶ packed into the chest cavity, resulting in the collapsing of the lung.¹⁵⁷ This method of collapsing the lung was not without flaws, generally the lung was collapsed for a short period of time to allow it to rest, however the wax used in the plombage technique could be difficult to remove.¹⁵⁸ Two of the most invasive surgical treatments were also introduced during this time, the lobectomy and the pneumoectomy. A lobectomy involved removing the diseased part of the lung, whereas a pneumoectomy was the total removal of a lung.¹⁵⁹ The first successful pneumoectomy performed at the Ninette Sanatorium occurred in

¹⁵¹ By 1970 all TB surgery was performed at Winnipeg General Hospital because the Ninette Sanatorium did not, "...have an intensive care unit, or the background to do major lung surgery." Earl Hershfield quoted in Maurice Mierau, *Memoir of a Living Disease: The Story of Earl Hershfield and Tuberculosis in Manitoba and Beyond*, Winnipeg, MB: Great Plains Publications, 2005. 42.

¹⁵² Stewart, *Holy Ground*, 65-6.

¹⁵³ Saskatchewan Lung Association, "Treatments of Tuberculosis: Thoracoplasty" <http://www.lung.ca/tb/tbhistory/treatment/thoraco.html> (accessed May 02, 2012).

¹⁵⁴ Stewart, *Holy Ground*, 66.

¹⁵⁵ Saskatchewan Lung Association, "Treatments of Tuberculosis: Thoracoplasty."

¹⁵⁶ Ping pong balls were used at some facilities; however I could find no record of this being done at the Ninette Sanatorium.

¹⁵⁷ Stewart, *Holy Ground*, 85.

¹⁵⁸ Ibid.

¹⁵⁹ Saskatchewan Lung Association, "Treatments of Tuberculosis: Lobectomy & Pneumoectomy," <http://www.lung.ca/tb/tbhistory/treatment/lobectomy.html> (accessed May 02, 2012).

1946.¹⁶⁰ Between 1935 and 1945, approximately 80% of all patients admitted to the Ninette Sanatorium received collapse therapy in one form or another.

One of the biggest developments in the treatment of TB occurred in 1944, when an American, Dr. Selman Waksman invented streptomycin.¹⁶¹ The medication became available in Manitoba in 1947, at which time it was only provided to those who could afford to pay for it, which was relatively a low percentage of patients.¹⁶² For example, in 1948 it was estimated 7.2% of Canadian TB patients were receiving streptomycin. By 1953 the figure jumped dramatically as the federal government had started supplying funding for streptomycin treatment and roughly 77% of Canadian TB patients were receiving streptomycin treatment at no charge.¹⁶³ In the 1950s, two other TB medications were introduced, *para-amino salicylic acid* in 1950 and *isonicotinic acid hydrazide* in 1953.¹⁶⁴ Patients were required to take all three medications for approximately 18 to 24 months and were prescribed all three medications to avoid drug resistance from developing.¹⁶⁵ Although effective medications were introduced and in use, collapsed lung surgeries were not discontinued at sanatoriums.¹⁶⁶

When TB rates peaked during 1953, approximately 15%¹⁶⁷ of sanatorium patients were Aboriginal.¹⁶⁸ Long, a member of the Pulmonary Research Group, University of Alberta, states

¹⁶⁰ Stewart, *Holy Ground*, 86; A.L. Paine, "Manitoba Perspective on Tuberculosis," *University of Manitoba Medical Journal* Vol. 52.1, 1982, p. 30.

¹⁶¹ Nobelprize.org, "The Nobel Prize in Physiology or Medicine 1952," http://www.nobelprize.org/nobel_prizes/medicine/laureates/1952/waksman-bio.html (accessed May 02, 2012).

¹⁶² Stewart, *Holy Ground*, 100.

¹⁶³ Saskatchewan Lung Association, "Time Line of TB in Canada: 1948 – Introduction of antimicrobials in treating tuberculosis patients," <http://www.lung.ca/tb/tbhistory/timeline/antibiotics.html> (accessed May 02, 2012).

¹⁶⁴ Stewart, *Holy Ground*, 100.

¹⁶⁵ Saskatchewan Lung Association, "Time Line of TB in Canada: 1948."

¹⁶⁶ Earl Hershfield, former provincial TB control director for Manitoba, found the Register of Operations reported that every major surgery performed at the Ninette Sanatorium between 1956 and 1970 had a 'good' postoperative outcome. Mierau, *Memoir of a Living Disease* 42.

¹⁶⁷ Grzybowski and Allen, "Tuberculosis: 2. History of the disease in Canada," 1026.

¹⁶⁸ Although 1% of patients were Inuit, there is no indication of who is included in the term Aboriginal. I am assuming the term is referring First Nations since the health care of Métis was covered by the provinces.

that in 1953 more facilities to treat TB patients were available than previously, and also Aboriginal peoples, specifically First Nations, were being admitted to sanatoriums, which was not the case during the 1930s,¹⁶⁹ and large scale TB surveys were being also being conducted. Although rates of TB did increase during the 1930s and 1940s, rates did decrease dramatically after the peak of the epidemic because of antibiotic treatment.

By 1960, Ninette was the only sanatorium that remained in operation in Manitoba.¹⁷⁰ As a result of the other TB facilities closing, Ninette experienced an increase in patients, most being Métis, Inuit, and Indian (First Nations). It was also during the mid 1950s that “salvage” surgery was introduced, which was performing either a lung resection or removing the lung.¹⁷¹ Dr. Paine, the Medical Superintendent at Ninette Sanatorium (1946-1972), reported this type of treatment began when the patient population at Ninette was mostly “White”.¹⁷² However, as previously noted, by the early 1960s the majority of the patients were Aboriginal, to which Paine stated “...our patient population had become mainly of native extraction. In these cases...there was poor cooperation both in long term sanatorium care and taking drugs at home, and recidivism was not uncommon.”¹⁷³ He furthered argued Aboriginal patients preferred salvage surgery, which as not effective, as a method of treatment. Paine’s own statistics found that only about 40% of patients undergoing this option were cured, 40% died, and the remaining 20% experienced little to no benefit from the surgery.¹⁷⁴

Overall, TB mortality rates in Manitoba dropped considerably from the 1940s to the 1980s. For example, in 1940 the death rates for non-Aboriginal TB patients was 50.8 per 100

¹⁶⁹ Long, “The Canadian Lung Association,” 428.

¹⁷⁰ Stewart, *Holy Ground*, 110

¹⁷¹ Ibid.; Paine, “Manitoba Perspective on Tuberculosis,” 32.

¹⁷² Paine, “Manitoba Perspective on Tuberculosis,” 32.

¹⁷³ Ibid.

¹⁷⁴ Ibid.

000, 4.3 per 100 000 in 1960, and 0.6 per 100 000 in 1980. Death rates also decreased among Aboriginal TB patients, from a high of 1 140 per 100 000 in 1940, 25 per 100 000 in 1960, and 4.4 per 100 000 in 1980.¹⁷⁵ Although mortality rates decreased dramatically among all populations, the rates decreased much slower among the Aboriginal population in comparison to the general population. Colonization was responsible for the social and economical marginalization of Aboriginal peoples, which was why the TB mortality rates remained elevated among the Aboriginal population in comparison to their non-Aboriginal counterparts.

NARRATIVES AND DISEASE

One of the primary ways Métis peoples and other Aboriginal peoples understand their history and the influence it has had, is through oral narratives. Garro and Mattingly (2000) explain,

Creating a narrative, as well as attending to one, is an active and constructive process – one that depends on both personal and cultural resources. Stories can [and do] provide a powerful medium for learning and gaining understanding about others by affording a context for insights into what one has not personally experienced.”¹⁷⁶

Wilson describes that as soon as an event or experience occurs it can become a part of the oral tradition.¹⁷⁷ For example, when a person is diagnosed with TB, the event can immediately become a part of the oral tradition, such as how the diagnosis was given by the physician or the immediate feelings the person experienced.

Oral tradition is a vital component of Métis culture. Wilson explains stories,

¹⁷⁵ Paine, “Manitoba Perspective on Tuberculosis,” 33.

¹⁷⁶ Linda C. Garro and Cheryl Mattingly. "Narrative as Construct and Construction." Chap. 1 in *Narrative and the Cultural Construction of Illness and Healing*, eds. Cheryl Mattingly and Linda C. Garro, 1-50 (Berkley, CA: University of California Press, 2000), 1.

¹⁷⁷ Angela Cavender Wilson, "American Indian History or Non-Indian Perceptions of American Indian History?" In *Natives and Academics: Researching and Writing about American Indians*, ed. Devon A. Mihesuah, 23-36 (Lincoln, NB: University of Nebraska Press, 1998), 23.

...provide moral guidelines by which one should live. They teach the young and remind the old what behaviour is appropriate and inappropriate in our cultures; they provide a sense of identity and belonging, situating community members within their lineage and establishing their relationship to the rest of the natural world.¹⁷⁸

Ultimately, oral accounts of events allow the listener to gain an understanding of historical events from someone's personal experience. In doing so, the individual is provided with a method of coping if the same situation arises or a means by which situations can be avoided. For example, if a person is told of a story of how someone became ill with TB, this individual may take the necessary precautions to prevent contracting the disease if put in a situation where TB is present.

Vast amounts of literature¹⁷⁹ discuss the importance of oral narratives, however, few scholars, if any, discuss the negatives. When examining narratives of illness, especially TB, it cannot be assumed the originator of the story is an expert, or even knowledgeable about the subject. For example, my grandmother was a TB survivor and told her family, as well as myself, she developed TB because a cook had spit in her soup; this is not a known method of transmission. Some of my grandmother's relatives who were told this narrative do believe TB is spread in this way. This research did find that misconceptions about TB do exist within existing TB narratives and as a result, listeners of these narratives are unaware of how to protect themselves if exposed to TB.

¹⁷⁸ Angela Wilson, "American Indian History," 23.

¹⁷⁹ Garro and Mattingly, "Narrative as Construct and Construction;" Linda C. Garro, "Cultural Knowledge as Resource in Illness Narratives: Remembering through Accounts of Illness," Chap. 3 in *Narratives and the Cultural Construction of Illness and Healing*, eds. Cheryl Mattingly and Linda C. Garro, 70-88 (Berkeley, CA: University of California Press, 2000); Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books Inc., 1988); Shawn Wilson, *Research is Ceremony* (Winnipeg, MB: Fernwood Publishing, 2008).

STIGMA, DISCRIMINATION, AND MISCONCEPTIONS

The literature and my research indicate that TB has always been associated with stigma, discrimination, and misconceptions and that this has continued to present day. Gray, explains stigma occurs in two ways,

Felt stigma (internal stigma or self-stigmatization) refers to the shame and expectation of discrimination that prevents people from talking about their experiences and stops them from seeking help. Enacted stigma (external stigma, discrimination) refers to the experience of unfair treatment by others.¹⁸⁰

Although Gray links discrimination to enacted stigma, Courtwright and Turner argue the aim of discrimination is to exclude, whereas stigma is to inflict shame or guilt.¹⁸¹

The stigmatization of those affected by disease is not a new phenomenon; it can be traced throughout history. Kleinman explains,

In the late Middle Ages, the Black Death (bubonic plague) depopulated the European continent by an astounding three-fourths. By so doing, the Black Death became a symbol of evil and terror. It came to signify several things: the wrath of God, man's fallen state of sin and suffering, and death as transcendence of the immortal soul. Whatever particular religious meaning the Black Death had for a community was overwhelmed by the immensely powerful practical meaning the term held for the afflicted and their families. The application of this label placed home and neighbourhood under the isolation of quarantine and made the inhabitants doomed outcasts who posed the gravest dangers to society.¹⁸²

Stigmatization of TB presents numerous challenges for those diagnosed with the illness.

Because most people do not understand how the disease is spread from one person to another, numerous misconceptions exist. In my research I have heard several narratives of TB transmission including, having sex with a prostitute, especially if the female is menstruating or elderly; being impure; eating certain food items; having a cold that continually gets worse until

¹⁸⁰ Alison J. Gray. "Stigma in Psychiatry." *Journal of the Royal Society of Medicine*, no 95 (February 2002): 72.

¹⁸¹ Andrew Courtwright and Abigail Norris Turner, "Tuberculosis and Stigmatization: Pathways and Interventions," *Public Health Reports*, supplement 4, vol. 125 (2010): 35.

¹⁸² Kleinman, *The Illness Narratives*, 18.

TB develops; working too much; sharing cutlery or cups; masturbating; and not doing up your jacket.¹⁸³ Farmer argues misconceptions about TB develop because people need to make sense of the disease as way to understand it.¹⁸⁴

Ignorance about TB not only occurs within Métis communities or on First Nations reserves, it also happens within the urban environment. In a survey conducted by Glover in Toronto, one respondent stated, "...I'm getting ready...if it is TB, I'm going to die. Because...my [relative] died of it [TB]. But back then it was lots of sunshine and everything else and that was it. And not much medications, so that scares me."¹⁸⁵ This man's fear was so intense that, "...[he] did not believe the doctors and nurses when they told him there was effective treatment available. He [the patient] thought their claim was a pretext to convince him to go to a quarantine hospital, where they would lock the door and he would live out his life."¹⁸⁶ In order to prevent fear and anxiety among those diagnosed with TB and to prevent misconceptions from persisting or developing it is essential public health messaging is made available.

The lack of public health messaging and the misconceptions associated with TB continue to present problems for TB patients. An added issue is that in comparison to other diseases such as H1N1 or HIV/AIDS, TB receives little media attention because the disease rarely affects the general population. Failing to provide adequate public health messaging that could address the misconceptions, in combination with the lack of attention the disease receives does result with

¹⁸³ Anecdotal evidence; Gibson et al., "Socio-cultural Factors," 936; Sheela Rangan and Mukund Uplekar, "Socio-Cultural Dimensions in Tuberculosis Control," in *Tuberculosis: An Interdisciplinary Perspective*, eds. John D.H. Porter and John M. Grange (London: World Scientific Publishing Co. Pte. Ltd., 1999), 268.

¹⁸⁴ Paul Farmer, *Infections and Inequalities: The Modern Plagues* (Berkeley, CA: University of California Press, 1999), 3.

¹⁸⁵ Chris Glover, *A Survey of Client Response to the Tuberculosis Directly Observed Therapy Program for Toronto Public Health* (Toronto: Health Promotion Consulting Group, 2006) 7-8.

¹⁸⁶ Glover, *A Survey of Client Response*, 8.

TB patients being socially stigmatized. For example, one newly-diagnosed TB patient reported his fear upon hearing his diagnosis, "...I was frightened. I don't care if you have proper time to sit down and have somebody explain it to you; fear is the thing you have to deal with personally as well as socially."¹⁸⁷ Typically, people fear the unknown, this combined with the lack of public health education and the existence of misconceptions have resulted in the illness becoming socially stigmatized.¹⁸⁸

The literature implies that stigma associated with TB can have repercussions such as patients not seeking medical care when symptoms appear, and when diagnosed, not adhering to treatment.¹⁸⁹ Brown argues stigmas surrounding illness can result in the development of taboos, which she defines as,

... taboo develops from punitive attitudes towards both the illness and person affected by the illness. It is about an illness, or a disease, judged as being so embarrassing or offensive that the personal experience of it becomes avoided, unmentionable, unprintable and untouchable. Taboo silences and, as it does, illness experiences are maneuvered into the realm of secrecy, away from public access and scrutiny.¹⁹⁰

A method to preventing a taboo from developing is to provide patients a way to express their illness experiences. Brown explains,

Giving voice to experiences of illness, giving words to them and claiming space and opportunities for the words to be read and listened to, restrains stigma from its progression towards taboo. When illness experiences are silenced, the

¹⁸⁷ Paul Draus, *Consumed in the City: Observing Tuberculosis at Century's End* (Philadelphia, PA: Temple University Press, 2004), 162.

¹⁸⁸ "Marie," Interviewed by author. Digital voice recording. Manitoba, February 14, 2011; Marketwire, "The Ontario Lung Association: Tuberculosis Remains a Health Concern in Ontario," <http://www.marketwire.com/press-release/The-Ontario-Lung-Association-Tuberculosis-Remains-a-Public-Health-Concern-in-Ontario-1136373.htm> (accessed May 06, 2012); Sharon Lem, "Alarming TB death rate among Toronto homeless," *Toronto Sun* February 17, 2011, <http://www.torontosun.com/news/torontoandgta/2011/02/17/17310066.html> (accessed May 06, 2012).

¹⁸⁹ Freda Festenstien and John M. Grange, "Tuberculosis in Ethnic Minority Populations in Industrialized Countries," in *Tuberculosis: An Interdisciplinary Perspective*, eds. John D.H. Porter and John M. Grange (London: World Scientific Publishing Co. Pte. Ltd., 1999), 326-7; Rangan and Uplekar, "Socio-Cultural Dimensions in Tuberculosis Control," 273.

¹⁹⁰ Janet Brown, "Silence, Taboo and Infectious Disease," in *Studies on Themes and Motifs in Literature*, eds. A. Mills and J. Smith (New York: Peter Lang, 2001), 83.

dynamics and transformations within which those experiences exist are also silenced. Illness experiences are a significant and complex part of the human condition. They deserve the right to be shared. It is only by challenging censure, resisting taboo and claiming the right to express and record personal experiences and insights about illnesses that these important stories can influence contemporary understanding.¹⁹¹

It appears the negative views of TB work in a circular fashion; misconceptions develop from fear and ignorance, which result in stigma and discrimination, both of which lead to the development of taboos. The taboos can then consequently elevate fear resulting in the cycle continuing.

POVERTY AND INEQUALITIES

Two major determinants of TB transmission are poverty and inequality. Typically, TB affects the poor and disadvantaged with the disease being ignored by the remainder of society. Not only does poverty increase the likelihood that TB infection will occur, it also affects the outcome of the disease. For example, if a patient cannot afford nutritious foods, the immune system will remain weakened allowing TB to remain active. Farmer argues that because the disease does not affect the wealthy it has become irrelevant. He further explains that this creates a problem since it is the wealthy and powerful that, "...control funding for everything from treatment to research."¹⁹²

Due to the ignorance of some government officials, policy makers, healthcare workers and academics, when TB is problematic and outbreaks occur blame is frequently placed upon the victim. For example, one study found, "Non-compliance on the part of patients is the most serious remaining problem in the control of tuberculosis and the chief cause of relapse and drug resistance."¹⁹³ Historically, institutions and organizations providing research funds have tended

¹⁹¹ Janet Brown, "Silence, Taboo and Infectious Disease," 90.

¹⁹² Farmer, *Infections and Inequalities*, 200.

¹⁹³ Stephen E. Weis et al, "The Effect of Directly Observed Therapy on Rates of Drug Resistance and Relapse in Tuberculosis," *New England Journal of Medicine* 330.17 (April 1994): 1182.

to be more concerned with the scientific aspects of the disease. Although this is slowly changing, and more funds are now available to examine the socio-economic, historical and cultural aspects of TB, failing to study these aspects earlier most likely resulted with the continuing spread of the disease. For example, the issue of poverty is not a new discovery in the world of TB, Allen Krause; a pathologist argued in 1923, “More or less poverty in a community will mean more or less tuberculosis, and so will more or less crowding and improper housing, more or less unhygienic occupations and industry.”¹⁹⁴ The Métis and other Aboriginal peoples have experienced the issues mentioned by Krause for well over a century, which is why TB has remained persistent among these populations.

SUMMARY

In summary, limited biographical accounts of Métis and other Aboriginal people’s TB sanatorium experiences exist. Examining the contemporary studies that do exist about Aboriginal peoples perceptions of TB, it appears the negative perceptions of TB held by individuals are directly linked to the sanatoriums and the treatments that were provided within these facilities.¹⁹⁵ For instance, some Aboriginal peoples can recall their loved ones being sent away for long periods of time¹⁹⁶, and “...often [removed from their families and communities] without being able to say goodbye.”¹⁹⁷ Although memories and narratives of former patients and their loved ones continue to influence contemporary Aboriginal people’s perceptions of TB, the majority of contemporary literature still tends to focus on the scientific and biomedical aspects of the disease.

¹⁹⁴ Farmer, *Infections and Inequalities*, 209.

¹⁹⁵ Funk, “Tuberculosis control among Alaska Native Peoples,” S27; Gibson et al, “Socio-cultural Factors,” 938.

¹⁹⁶ Funk, “Tuberculosis control among Alaska Native Peoples,” S27.

¹⁹⁷ Qikiqtani Inuit Association, “Qikiqtani Truth Commission.”

Oral narratives remain relevant among the Métis. Not only do oral narratives transfer knowledge from one generation to the next, the process also allows the storyteller to pass along their own experiences in their own words. However, existing literature pertaining to the importance of Aboriginal oral narratives generally fails to mention the negative ramifications that can result. In fact, consequences of oral testimonies provided by TB patients can result with incorrect information being passed along to others, resulting in fear, increased stigma, as well as discrimination and misconceptions.

Not only have narratives of TB contributed to stigma, discrimination, and misconceptions; additionally responsible is the lack of public health messaging. This is problematic because if TB patients are ignorant about the modes of transmission and treatment, they may create their own scenario as to how they acquired the disease, such as in my grandmother's case. And, although my grandmother was not passing along incorrect information intentionally, it did result with misconceptions developing.

CHAPTER 5 METHODOLOGY

Narrative inquiry is a qualitative process involving the collection and interpretation of an individual(s) experience through storytelling, which in turn provides meaning to the narrator's human experience.¹⁹⁸ Various forms of stories can be collected and analyzed using this method, such as "...autobiographical, biographical, [and] testimonial"¹⁹⁹ accounts. This qualitative process involves conducting semi-structured interviews about specific personal experiences. The knowledge collected during the interview process is then combined with the researcher's personal experience to create a new narrative.²⁰⁰ Unlike quantitative methods, narrative inquiry uses words instead of numbers to avoid losing the human experiences that are found within the stories. Once the narratives are transcribed, the data from both the transcripts and field notes are broken down into categories, which are then analyzed to determine what themes exist.²⁰¹

USING NARRATIVE INQUIRY IN THIS STUDY

When determining what naturalistic approach would be best to complete the research and establish respect and relationships with the participants, it became apparent that narrative inquiry would best serve to answer the questions posed in this study, such as: was it your [mom, sister, grandfather, cousin] that had TB; did she ever say how she got TB; did she have to go to a sanatorium for treatment; did she talk about the sanatorium at all; why do you think your [mom, sister, grandfather, cousin] got TB and not their [the spouse, children, siblings]; have you heard any of the Old People in your community talk about it; do you think TB is still an issue; and how

¹⁹⁸ Sheila Danko, Jason Meneely, and Margaret Portillo, "Humanizing Design through Narrative Inquiry," *Journal of Interior Design* 31.2 (2006), 11; Elizabeth DePoy and Laura N. Gitlin, *Introduction to Research: Understanding and Applying Multiple Strategies* (St. Louis, MI: Elsevier Mosby, 2005) 118;

¹⁹⁹ Elizabeth DePoy and Laura N. Gitlin, *Introduction to Research: Understanding and Applying Multiple Strategies* (St. Louis, MI: Elsevier Mosby, 2005), 118.

²⁰⁰ Danko, Meneely, and Portillo, "Humanizing Design through Narrative Inquiry," 11.

²⁰¹ University of Wisconsin-Extension, "Analyzing Qualitative Data," <http://learningstore.uwex.edu/assets/pdfs/G3658-12.PDF> (accessed May 11, 2012).

do you think a person gets TB.²⁰² Not only does this method involve storytelling but it also allows the researcher to “...focus on understanding and interpreting human experience within the context of which [the] experience occurs.”²⁰³ The naturalistic approach simultaneously allowed the participants to share their knowledge and experiences with me while at the same time I was able to collect the data for this study.

While designing my research plan I wanted to be sure that I could fully answer the questions posed in this study. Smith explains that when conducting Indigenous research, one must frame the issue, which is not just designing a research question and answering it, but looking deeper at, “...what is in the foreground, what is in the background, and what shading or complexities exist within the frame. The project of reframing is related to defining the problem or issue and determining how best to solve that problem.”²⁰⁴ She explains that in order to find solutions to problems some Aboriginal communities are incorporating initiatives that, “...address the whole community, its history and its wider context as part of the problem and part of the solution.”²⁰⁵ Therefore, in order to understand how narratives among the Métis influence perceptions of TB, this research did not solely focus on contemporary issues it also examined how colonial practices influenced the lives of the Métis.

As mentioned previously, narrative inquiry allows for the creation of a new narrative. In this case, the new story is a collaboration of the participant’s recollections and my own. There are a number of positives aspects that result because of this, such as: providing insight into how the Métis experience and perceive TB; understanding how colonialism has affected the Métis

²⁰² Refer to Appendix A for a full listing of the interview questions.

²⁰³ Depoy and Gitlin, *Introduction to Research*, 7.

²⁰⁴ Linda Tuhiwai Smith, *Decolonizing Methodologies: Research and Indigenous Peoples* (New York, NY: Zed Books, 1999) 152.

²⁰⁵ Ibid.

historically and how contemporary Métis peoples continue to be affected by the negative impacts of colonization; as well as to provide the Métis a presence within TB literature.

POSITIONING THE RESEARCHER

Prior to starting data collection I knew I wanted to create a strong relationship with the participants that would expand beyond just a researcher-participant rapport. Using Fixaco's argument that a researcher must put themselves in the shoes of the person they are interviewing, to establish truth and balance;²⁰⁶ I felt it was important to begin by telling the participants about my grandmother's TB experience. I feel this improved the relationship that I established with the participants, becoming more complex than just a researcher-participant connection. Sharing my family's TB narrative with the study participants helped establish a mutual respect between us, as well as it explained to the participants my reasons for wanting to undertake this research.

People often question me as to why I am interested in researching TB, since most individuals believe it is a historical disease and is no longer a threat to the health of Canadians. However, I grew up with a grandmother who experienced firsthand what it was like to be a Métis woman infected with TB. Her disease not only had a tremendous effect on her life, but also on four generations of my family. I heard many stories of her struggles living with TB, including how my mother and her sister were affected by their mother's illness. Although my grandmother passed away in 2003 her stories continue to be told among my family members. While my grandmother's stories were rarely pleasant she would often tell in graphic detail her experiences at the Ninette Sanatorium and with the healthcare system.

²⁰⁶ Fixico, Donald L. "Ethics and Responsibilities in Writing American Indian History." In *Natives and Academics: Researching and Writing about American Indians*, ed. Devon A. Mihesuah, 84-99. University of Nebraska Press, 1998, 93.

In order to understand how TB historically shaped the lives of infected individuals and their families, a brief glimpse into the life of my grandmother, Gertie Morsette, serves as a useful example. Gertie was born in 1924 in Manitoba and was the seventh child in a family of nine. Her family was poor and her father died when she was 14 years of age. Of all her siblings, Gertie managed to get the highest education, grade 9. In 1943, she was unwed and had her first daughter, Bella. In the winter of 1944, Gertie married Lawrence Dubois, a soldier who had recently returned from fighting overseas.

In 1945, Gertie became sick with cold like symptoms. These symptoms were persistent for many months and numerous times Gertie went to her doctor to determine the cause of her symptoms. Each time the physician would tell her she was just run down and would eventually recover. However, Gertie's coughing persisted until she began bringing up blood stained sputum.²⁰⁷ Finally, Gertie went to see a different physician; upon hearing her explain her condition, the doctor said he did not even have to examine her and diagnosed Gertie immediately with TB. Gertie was told she would have to be sent to the Ninette Sanatorium for treatment.

Upon hearing she would be sent to Ninette Sanatorium, Gertie sold her bedroom suite to her sister, packed up her clothing to leave at her mother's house, and made arrangements for her mother to take care of Bella.²⁰⁸ Gertie often said she did not fully understand how sick she was until she got to the train station, where she and another young First Nations woman were placed into a train car in isolation. She said none of the train staff were allowed to enter the train car.

²⁰⁷ When my grandmother spoke of her blood stained sputum she always referred to it as hemorrhaging.

²⁰⁸ While overseas Lawrence lost his right arm in battle and when he returned to Winnipeg, he began drinking excessively. While Gertie was in Ninette Sanatorium Lawrence did not have a permanent address and his drinking problem worsened. Bella does remember Lawrence staying at her grandmother's house sometimes but said that he would leave to go drinking when he received his monthly army cheque.

When they arrived at Ninette, she and the other woman were escorted off the car and immediately admitted to the sanatorium.

While at the Ninette Sanatorium, Gertie received few visitors because her family was poor and the sanatorium was over 200 kilometres from Winnipeg, where they lived. As a patient, Gertie was put under strict bed rest, meaning she was not allowed out of bed for any reason. She had to eat in bed and was not allowed to bath, neither in a bathtub nor a shower.²⁰⁹ She often spoke about how she would lay in bed for hours with tears streaming down her face, continually repeating to herself, “I must get well.”

Gertie became friends with Amelia, the woman whose bed was beside hers. At night they would sneak into one another’s bed to comfort each other and to have some human contact. Gertie often spoke of the old elevator and how when they heard it creaking in the night they knew someone had died and the body was being taken to the morgue. She remembers many patients having surgeries and some being forced to lie in bed with heavy weights on their chests to collapse their lungs.

My grandmother had few positive things to say about her experience at the Ninette Sanatorium. Other than friendships with a few patients, the only other positive things she spoke about were the food and the staff. She told stories of how when it was duck hunting season the doctors would donate their kill to the hospital. She spoke of how the meals consisted of eggs, butter, fresh vegetables and milk. Gertie recalled the picnics held on the sanatorium grounds for staff and their families; and that the patients who were not infectious were also allowed to attend. Gertie was never allowed to attend; instead, she would lie in her bed on the screened balcony and enjoy the music and watch the plays put on by the staff.

²⁰⁹ She was given a sponge bath while in bed.

When Gertie was first admitted to Ninette Sanatorium, there were no medications to treat TB. However, while she was in the sanatorium streptomycin was invented.²¹⁰ The doctor approached Gertie and explained that a probable cure had been discovered. She was elated until he said patients wanting the new treatment would have to pay for the costly drug themselves. Gertie told him that neither she, nor her family could afford the treatment. Ernie, Gertie's older brother, visited her shortly after this, and without her knowledge paid for a full course of streptomycin treatment. Gertie began treatment immediately and before long she was in recovery.

Patients who were no longer infectious were allowed to go out with visitors for short drives, but were not permitted to go into stores or restaurants. My mother, Bella, recalls her grandparents taking her to visit her mother. Children were not allowed in the sanatorium and my mother remembers standing at the door crying because she wanted her mother. Gertie and her family did not have much money and in 1947 when she was discharged, they had no money for her train fare to return to Winnipeg. After waiting several days, the staff had collected enough money for Gertie to return home.

When Gertie returned home she found her husband Lawrence had been spending all his army cheques on liquor instead of saving it to purchase a home as he promised. All her things, such as clothes, had been given away to her sisters because her mother believed she would not survive. Gertie left Lawrence and took her daughter and went to live with her brother, Ernie and his family in Port Arthur, Ontario. Not long after, Gertie discovered she was four months pregnant with her second child. She returned to Winnipeg immediately and reconciled with

²¹⁰ Streptomycin, discovered in 1944, was the TB medication that was not only safe for human consumption but also was effective in treating TB. Saskatchewan Lung Association, "Treatment of Tuberculosis: Antibiotics," <http://www.lung.ca/tb/tbhistory/treatment/antibiotics.html> (accessed August 04, 2011).

Lawrence. Gertie was advised by her doctor to have an abortion because it would be too hard on her health to carry a baby. She refused to terminate the pregnancy and in 1948, her second daughter was born.

When the baby was three months old, Gertie's worst fear came true; her TB was infectious again and she was ordered to return to Ninette Sanatorium. My mother Bella does not recall visiting Gertie during this stay. She thinks it may have been too difficult for her grandmother to take her there because she was not only raising Bella and her sister, but also another granddaughter.

Gertie was released in 1949 from the sanatorium and returned to Winnipeg. Lawrence, Gertie and the two girls moved to the North End and Bella began grade one. Although Gertie was not infectious, she was still required to undergo pneumo.²¹¹ By now, Lawrence was a chronic alcoholic and he would often cash his veteran's cheque and take off, leaving Gertie and the girls with nothing. Two of Gertie's sister tried to help but they had their own families to take care of. During this time Bella missed a lot of school, which resulted in her repeating grade one. Gertie became pregnant for the third time, however this time she took the advice of the doctors²¹² and had an abortion.



Prior to Gertie being sent to the Ninette Sanatorium the second time her family had a going away party for her.
L-R: Bella, Gertie, Francis (Gertie's sister-in-law), and Gertie's brother, Ernie.
1948, Winnipeg

²¹¹ Pneumothorax is collapsing of the lung by inserting a needle through the ribs and pulling the air out of the lung.

²¹² At the time, more than one physician had to agree that an abortion was necessary.

Life was difficult for Gertie as her body was weak and she experienced bouts of coughing and bringing up phlegm. As children, neither Bella nor her sister, were allowed to tell anyone that their mother had TB, it was to remain secret. Gertie always believed she was going to die and therefore Bella needed to learn how to cook, clean, and take care of her younger sibling. Bella recalls that none of them had any close friends and the only visitors they received were family, and even they did not visit often.



Nellie (Gertie's sister) visiting Gertie at Ninette.
L-R: Gertie, children, Nellie (Gertie's Sister)
c. late 1940s, Ninette, Manitoba

Around 1951, Gertie separated from Lawrence for the last time and sent her youngest child to live with her mother. Bella remained with Gertie, still residing in Winnipeg. Although Gertie's doctor advised against it, she worked as a waitress. The pay was low and the employers either never knew she had TB or did not care. Throughout this time, Bella and her sister were tested on a regular basis for TB. Originally, they were given a skin test, but both had positive reactions causing them to have high fevers and their arms to swell. The skin testing was ceased, and instead, they were given a chest x-ray once a year. To this day my mother still goes for chest x-rays, although not as often.

In 1955, Gertie was diagnosed again with active TB and admitted to St. Boniface Hospital in Winnipeg. She was now in a new relationship with Norman (who I know as Grandpa). My mom recalls going with Norman to see Gertie while she was in the hospital. Again it was recommended that Gertie be sent to the Ninette Sanatorium for treatment. After being in the sanatorium for a couple of months, Gertie escaped with the help of Norman. She

arranged for Norman to pick her up in the dark of night, which he did, and they (including Gertie's two daughters) headed for British Columbia. In April of 1956, they moved to Vancouver after living in Fernie, BC. My grandmother disliked Vancouver. All her family was in Winnipeg, she had no friends, her family was financially broke, and Norman had gone to work as a logger in the bush.

Before long, Gertie fell ill again and in 1957, she was admitted to George Pearson Centre, a facility designed to treat those affected with TB or polio. By now, her TB had caused her lungs to become like honeycomb²¹³, which she thought doctors could repair surgically. However, the doctors said they could not and after nine months of being institutionalized she went against their advice and told them she was going to go home to die. The physicians gave her six months to live if she left, but she left anyway. Gertie talked about going for needles after she left the facility but never mentioned what they were for. The needles made her ill and upon returning home from the treatments she would collapse on her bed. The needles also affected her balance and eyesight. In addition, she had to provide sputum samples, which were sent to the TB clinic to determine if she was infectious or not. My grandma told me that in those days if you had active TB and refused to go to the hospital, the police would arrest you and take you to George Pearson Centre where you were locked up.²¹⁴

²¹³ Healthy lungs are elastic, allowing them to contract and expand when a person breaths. Respiratory diseases such as TB and pneumonia can cause scarring of the lung, reducing elasticity. The stiffening of lung tissue does affect respiratory function and results with the lung looking similar to honeycomb (similar to honeycomb found in a bee hive). Honeycombing of the lungs can result in respiratory failure. *Oxford Medical Dictionary*, 337.

²¹⁴ My grandmother and my mother both told me about a room at the George Pearson Centre where patients were locked in similar to jail when they would not comply or refused treatment. In July 2011, a Winnipeg woman with active infectious TB was placed in a correctional institute because she refused to comply with the treatment regime. Mike McIntyre, "Tuberculosis Keeps Woman in Jail," *Winnipeg Free Press*, July 30, 2011, <http://www.winnipegfreepress.com/local/tuberculosis-keeps-woman-in-jail-126446388.html> (accessed August 01, 2011).

Gertie continued to have chest x-rays and sputum tests done to ensure her TB was inactive. She never wanted anyone to know about her illness, it was a secret never to be told to anyone outside the family. When the secret did get out, although it did not happen often, Gertie and her children were treated differently. For example, my mother recalls having a friend whose parents would occasionally invite her to spend the night with their daughter. Somehow, the girl's parents found out about Gertie's TB and they would only allow sleepovers if Gertie was in the hospital, never when she was at home.

Gertie's sides were always tender from the pneumo treatments, so tender it would bother her to wear a bra. I also remember each time my grandmother did the dishes, scalding water was poured over each dish to kill off any germs. Gertie stayed out of the sun, believing it would make the TB germs in her system stronger, and I can remember that if my grandmother was in direct sunlight too long she would get ill. When Gertie had a cold she did not want or allow her family to come in close contact with her. Each time she became sick with a cold, her immediate reaction was to think her TB was back again. Trying to take her to the doctor because of cold symptoms was extremely difficult because Gertie always believed that if she went to see the doctor, she would be sent to the sanatorium again.²¹⁵ Gertie never planned things too far in advance; every aspect of her life was affected by her fear that her TB would return.

I would like to be able to say that my family is educated about TB, but most are not. For example, when Gertie's second great grandchild was born, his mother called Gertie and said she did not want her to hold the baby. When my grandmother asked why, my cousin responded by saying she did not want her baby to get sick with TB. My grandmother lived for her

²¹⁵ Gertie often spoke of having nightmares of being sent back Ninette Sanatorium. In the 1980s, my mother took my grandmother to see the grounds of the Ninette Sanatorium, which was no longer in operation. My grandmother said once she saw the facility was no longer in operation, her nightmares of being sent back stopped.

grandchildren and great grandchildren and this ignorance was heartbreaking for her. Even though it had been almost thirty years since my grandmother had active TB, her own grandchild did not understand the basics of TB transmission.

One thing Gertie did that she believed made her equal to others was to drink alcohol. When drinking alcohol she no longer felt like a TB victim, she was an equal, and she never told anyone she drank with that she had TB. Gertie refused to take the advice²¹⁶ of the doctors, choosing to live the way she wanted. For example, with only one-fifth of a lung that functioned, Gertie continued to smoke cigarettes. When I look back I question why my grandmother never planned anything in advance. I believe she felt this way because of the countless times she was told she would not survive, thereby making it nearly impossible for her to fathom the idea of survival.

On July 13, 2003, my grandmother passed away.²¹⁷ In August 2003, I relocated to Brandon, Manitoba to start my post secondary education. During this same month, my mother phoned to inform me our family physician in Vancouver suggested that everyone who was in contact with my grandmother to be tested for TB. I made an appointment with a physician in Brandon and told him I needed to be tested for TB. The doctor, originally from South Africa, said he would not order the test because TB did not exist in Canada. After much discussion and explaining why I needed to be tested, he reluctantly provided me with the requisition. None of my immediate family tested positive, yet the fear does exist that it could happen.

Since Gertie was so adamant that her experience with TB was to remain a secret, I had never really heard of TB mentioned outside of my family until my second year of university. I

²¹⁶ Doctors had told Gertie to avoid consuming alcohol and smoking. She was also advised to eat healthy foods and get proper rest.

²¹⁷ TB was a factor in her death as noted on her death certificate.

was taking a course that focused on Aboriginal people and health issues. During one of the lectures, the professor spoke of how TB was still a health problem among Aboriginal peoples. This surprised me since I, myself, did not realize the disease was present. One of the course requirements was to write a paper, which I wrote about TB and Aboriginal people. When my paper was returned, the professor told me that I should expand my paper, and ultimately developed it as my undergraduate thesis.

While compiling information for my undergraduate thesis I found that public health messaging about TB is almost non-existent in western Manitoba or elsewhere in Canada.²¹⁸ In addition, what little information exists is often based on the scientific aspects of the disease and little attention, if any, focuses on patient perceptions of the disease or how it affects the family and community. I believe because the disease is not spoken about that it is making the TB problem worse. If perceptions held by patients and families are documented and education made available, the disease burden could be reduced so other individuals can avoid contracting the disease.

PARTICIPANTS

This study involved five Métis women,²¹⁹ all of whom had a family member(s) infected with TB. Each of the women met the criteria to participate in study, which entailed: 1) being recognized by the Manitoba Métis Federation as Métis²²⁰, 2) been diagnosed with TB or a close

²¹⁸ When gathering information I contacted the Manitoba Lung Association to ask them for the pamphlets they send to northern Aboriginal communities. The woman (confidential) told me these pamphlets were old and outdated and would be of no value. I asked why if these pamphlets were no longer of use why they were continuing to use them and she replied they wanted to get rid of them without having to discard them.

²¹⁹ I did not intend to only interview females, however they were the only ones willing to participate in the study.

²²⁰ The definitions and applications for membership defined by the Manitoba Métis Federation include: (a) "Métis" means a person who self-identifies as Métis, is of historic Métis Nation Ancestry, is distinct from other Aboriginal Peoples and is accepted by the Métis Nation. (b) "Historic Métis Nation" means the Aboriginal people then known as Métis or Half-Breeds who resided in the Historic Métis Nation Homeland; (c) "Historic Métis Nation Homeland" means the area of land in west central North America used and occupied as the traditional territory of the Métis or

relative of a TB patient, 3) reside in the southwest region of Manitoba, and 4) be over the legal age of eighteen. Participants varied in age, with the youngest being in her early 40s and the oldest being in her early 80s.

Prior to beginning the interviews, I explained to each participant what the study was about, what I hoped to achieve, and why I had chosen the topic. Understanding how sensitive the topic can be, I explained how my grandmother's experience with the disease affected, and continues to affect my family. After doing so, each participant seemed to become more relaxed. In addition, I also use my grandmother's experience with TB during the interview to determine if any of the participants' relatives had similar experiences.

Originally, the interviews were to be one hour in duration, however the average interview time was approximately half an hour. The reason the recorded interviews ran short of the desired time was because when I was speaking to participants to arrange an interview the participants provided plenty of information in regards to their relative's experiences and provided consent to use the data. Therefore during the actual interviews I did not find it necessary to try and acquire the same information they had already provided which was recorded in my field notes.

Each interview was digitally voice recorded and transcribed by myself. I allowed each participant to choose the location for the interview; this allowed the participant to choose a setting they would be most comfortable with. Three interviewees preferred to have the interviews conducted at their place of business and two opted to invite me into their homes.

Half-Breeds as they were then known; (d) "Métis Nation" means the Aboriginal people descended from the Historic Métis Nation, which is no comprised of all Métis Nation citizens and is one of the 'aboriginal peoples of Canada' within s.35 of the Constitution Act of 1982; (e) "Distinct from other Aboriginal Peoples" means distinct for cultural and nationhood purposes. In addition, when applying for membership to the MMF the applicant must provide a detailed genealogy and supporting evidentiary documents to verify his or her Historic Métis Nation Ancestry. Manitoba Métis Federation. *Constitution*. Winnipeg, MB: Manitoba Métis Federation (2008), 2.

Participants provided written consent and each was asked the same questions [Appendix A]. However, because I had spoken to the participants prior to the interviews, and they each had told me which of their relatives was affected by TB, I changed the questions accordingly. For example, instead of asking how they were related to the individual I asked if it was their cousin, grandfather, mother, sister, etc. This allowed the questions to be more personal and it was easier to change the questions prior to the interview, rather than during it.

RECRUITMENT PROCESS

In order to find participants for the study, posters, word of mouth, and formal letters were used. Letters outlining the study were sent to each MMF local (18 in total) within the southwest region²²¹ on three separate occasions. In addition, posters were placed at the MMF-SW region head office in Brandon, Manitoba and their sub-office in Portage La Prairie, Manitoba. The MMF-SWR also allowed me to place a recruitment poster on their website and within their office. The snowball technique was also utilized, requesting participants to inform their friends. Lastly, in order to find physicians and other healthcare professionals, formal letters were sent to each physician and medical clinic within the southwest region twice.²²²

CHALLENGES OF RECRUITMENT

The recruitment process was challenging, frustrating and slow, not because I could not find individuals who had family members affected by TB, but because of the lingering stigma associated with the disease. I encountered approximately fifteen individuals, excluding those whom I did interview, who had close relatives who were diagnosed with TB and were willing to share their stories. However, when I mentioned that I was doing research about TB they would

²²¹ The southwest region of Manitoba was chosen for my study for two reasons; 1) I was primarily interested in interviewing those who had relatives in the Ninette sanatorium, and 2) to have access to the staff, many of whom I know personally, and library facility at Brandon University.

²²² In order to locate the various physicians, telephone books were utilized to located names and addresses.

say they did not know anything or if they did agree to participate they would change their mind. For example, in February of 2011, I attended a large Métis gathering and approached²²³ a number of individuals and asked if they knew anyone who had TB. One Elder told me her father had TB and was admitted to the Ninette Sanatorium.²²⁴ She told me a number of stories about his stay at the sanatorium, but when I told her about my project and asked if she would be willing to participate she said she did not remember anything. I did explain the stories she just told me was what I was looking for, but she refused to be interviewed. Later I spoke to her cousin²²⁵ who told me that she was surprised she had mentioned that her father had TB because similar to my family, his experience with TB was to remain a family secret.

Other individuals were willing to participate but continually had reasons as to why they could not meet with me. For instance, I met a friend who I had not seen for approximately a year. She asked what I had been doing, which I responded that I was working on my graduate thesis and explained my topic. She told me her grandfather had TB and was admitted to the Ninette Sanatorium. We shared information about our loved one's TB experience and I asked if she would allow me to interview her for my study. She told me that instead of interviewing her that I should interview her mother and she would be willing make the arrangements. That evening I sent her an email with a description of my project, the interview process, and how the information would be used. She responded and stated her mother would be more than willing to participate. Arrangements were made for the interview, but a few days prior to the interview, my friend emailed stating that because of weather conditions we would need to reschedule. The

²²³ I did try approach individuals in private since I know that some people will not admit they know someone, especially a family member, who had or has TB.

²²⁴ Taking the Elders age into consideration I would assume her father was admitted to Ninette Sanatorium between the mid-1940s to the early 1950s.

²²⁵ This individual also spoke of her uncle's experience but refused to participate in this study.

interview was rescheduled at a mutually convenient time and again, my friend emailed indicating that mother was concerned about her failing memory and was not sure she would be able to remember anything. I once more asked my friend if she would be willing to participate and again told it would be better if I interviewed her mother. After numerous emails, the mother and daughter did agree to sit down with me together to be interviewed. Approximately a week prior to the interview the daughter emailed to say they were unable to make the appointment and that it would probably be best if I found someone else to interview. These two women seemed fine with me knowing their loved one had TB and sharing their narratives with me, but yet they provided numerous reasons to avoid being formally interviewed.

As mentioned, the individuals I met who had loved one's with TB were more than willing to share their stories with me in casual conversation, answer any questions, but refused to participate in my study. Upon asking if they would participate most responded by stating they did not know anything about the topic. When I told them what they had already shared was what I was looking for they generally said no thank you. I believe there are a number of possible reasons why these individuals did not want to participate in this study, including: upsetting their families; the idea that the narrative was not theirs; sharing unpleasant memories; feeling they could not provide a totally accurate account of their loved one's story; thinking that the story was not important; or the fear of having their story recorded and documented. I think the lack of education and awareness about TB contributed to people not wanting to share their stories. Introducing of public health education could possibly increase participation in future studies by reducing stigma, fear and acknowledging TB remains problematic. Listening to the various narratives, both by those who participated and those who did not, was helpful in completing this study by providing a wider understanding of TB narratives. In addition, hearing the narratives of

those not interviewed allowed me to see the similarities and difference in how narratives are constructed. I do not believe the narratives of those not involved in the study hindered the research, but it did delay the research process.

RESEARCH PROCESS

Field research began in March 2010, when ethics approval was obtained and lasted until the end February 2011. During this time I resided in Brandon, Manitoba, which is centrally located within the boundaries of the southwest region.

Ethics

This study required both worldviews be incorporated, which at times was awkward, difficult, and confusing. For example, the university required written or oral consent be provided by all participants. However, when asking the participants to provide consent, they all appeared to become uncomfortable and asked why this was required. I did explain it was a mandatory part of the research to protect²²⁶ not only them, but everyone involved, to which one participant said, “a narrative is a gift and when told, it is already understood the story is to be shared among others, so just listening to the story should be consent enough.”²²⁷ This individual continued to say I should already know this because of my background²²⁸, and again I had to explain it was a required part of the research process. Once I had explained why consent was required and promised each participant I would not alter their stories or portray them in a negative way, each provided written consent.²²⁹

Confidentiality

²²⁶ When I said the word ‘protect’ all participants asked me to repeat exactly what I was going to do with the information. I did explain the consent was to ensure their names would remain confidential and that the information would be interpreted to the best of my abilities to determine if narratives influence Métis people’s perception of TB.

²²⁷ “Marie,” Interviewed by author. Field Notes. Manitoba, February 14, 2011.

²²⁸ All participants had knowledge that I am Métis.

²²⁹ I did offer the participants the option to provide oral consent. However, once I had explained why consent was required they all agreed to provide written consent.

The consent process [Appendix B] entailed administering a written document describing how the material would be used, a disclosure of confidentiality, how the information (i.e. digital recordings, transcripts, etc) would be stored, as well as the rights of the participants. After disclosing the previous information and prior to commencing the interview process, a signature of consent was obtained. All participants were comfortable with signing the consent form and no verbal consent was given. In the case of my mother, whose name I did use, a separate waiver of confidentiality [Appendix C] was used and approved by Ethics.

To ensure the confidentiality of each participant, all identifying words, phrases, and references were removed from the transcribed material. Except for my mother and my deceased relatives, every participant's name, as well as their relatives, was replaced with a pseudonym in order to identify them within the thesis. Participants were also told they had the right to decline answering any question they wished. As well, they were informed they had the right to withdraw from the study at any point without penalty.

Each participant was asked the same question, but as previously mentioned the questions were altered to reflect how the interviewee was related to the person who they were speaking of (e.g. grandfather, mother, sister). Upon completing all interviews, the answers provided by the interviewees were combined under each separate question and then analyzed to determine if any themes or patterns emerged.

After transcription was completed by the researcher, each participant was given the option of reviewing their transcript and requesting certain information be removed prior to analyzing the data. However, none of the participants opted to review their transcripts. All material, digital voice recordings and transcript files are password protected and stored on a jump drive that is also password protected. In addition, backup copies of all materials are stored

on a DVD, and again all material is password protected. All materials (i.e. digital voice recorded and transcript files) are securely stored in my place of residence. Lastly, in order to thank each person for participating in the study a gift consisting of a mug and tea was given.

TRANSCRIPT & DATA ANALYSIS

All interviews were digitally voice recorded and transcription began immediately upon completing each interview. The recordings were transcribed *verbatim* into individual Word documents. As each interview was transcribed, a copy of the original file was created and the corresponding field notes were added in a different colour to distinguish them from the interview. Additional notes were also added at this time, such as topic changes and any noticeable changes in vocal tones and body language. The next step involved listing all the research questions in a new file, copying and copying and pasting all the participant's answers as well as field notes and additional notes that were related to that question. Underlying themes were present within the questions such as what form of TB the patient had, the sanatorium experience, how the person got TB, was bad medicine involved and education. Once all the information had been transferred over, the data was examined to determine commonalities and differences. As new themes emerged, I tried to determine how they were interconnected to one another and to the main topic. It was also at this time that information that was not critical to the research was removed.

Interpretation of the data began once I had established how the main themes and the minor themes were related. During the interpretation phase, three aspects need to be explored, which are temporality, society and location.²³⁰ Temporality involves looking at the various time

²³⁰ D.J. Clandinin and J. Huber, "Narrative Inquiry," in *International Encyclopedia of Education*, 3rd ed. eds. B. McGaw, E. Baker, & P. Peterson (New York, NY: Elsevier, nd),

periods, which are the past, present and future of the participant's lives as well as the researchers. In doing so, it allows for a better understanding of how stories can change over time. Sociality is the examination of conditions that have, or are, influencing the narrative. For example, if the relationship between the researcher and participant is troubled, a participant may not provide as many details in the narrative, whereas, a respectful relationship may result in more details being provided. The last aspect, location, is important because, "...our identities are inextricably linked with our experiences in a particular place or in places and with the stories we tell of these experiences."²³¹ Each of these factors was kept in mind during the interpretation phase in order to provide an accurate account of the narratives during analysis.

The words of the participants are crucial to this study and where possible I tried to use their exact words. I felt this would allow the reader to better understand the narratives and the impact they possess. Additionally, I believe it is easier to place yourself within the experiences of the participants when their own words are used, expressing their thoughts, emotions, and knowledge. By appreciating the stories of the participant's and presenting them as accurately as possible allowed a new theoretical understanding to emerge.

SUMMARY

This chapter describes narrative inquiry as the primary means by which data were collected for this project. This approach involves collecting personal stories from participants using semi-structure qualitative interviews. Once the data were collected and transcribed, the data was sorted by the interview questions to determine if any commonalities and differences existed. Once analyzed, they were combined with my own experience to create a new theoretical

<http://www.mofet.macam.ac.il/amitim/iun/CollaborativeResearch/Documents/NarrativeInquiry.pdf> (accessed May 11, 2012), 3.

²³¹ Ibid., 4

understanding to be achieved through the development of a new narrative. Incorporating my personal experience as well as sharing them with the participants allowed relationships to be established that go well beyond a general researcher-participant relationship.

Recruiting participants was the most difficult aspect of this study. Although it was not difficult to find Métis individuals who had TB or had loved ones with the disease, many did not want to share their stories in the way of a formal interview. However, they were more than willing to speak to me in an informal setting, indicating stigma is still associated with the disease. No ethical concerns arose during the research process and those involved in the study were ensured confidentiality by the removal of all factors that could possibly identify them, such as: names were replaced with pseudonym, names of communities were not mentioned, all words and phrases and references from the transcribed material was removed.

My grandmother's experience is included to position me within the research as well as to provide an understanding to the reader of how TB affected the lives of the patients, their families and communities. Analysis of my own narrative and those of the participants resulted in a number of themes that are the basis of the following chapter.

CHAPTER 6

DATA ANALYSIS & DISCUSSION OF FINDINGS

The focus of this chapter is to introduce the participants and their relatives.²³² This provides a deeper understanding of who they are and helps to show the commonalities between them, such as the knowledge each had about the disease. Next, a discussion of the findings are presented, focusing on the similarities and differences that were found, such as poverty, limited knowledge of tuberculosis, the loneliness experienced by the participants' relatives while they were at the sanatorium, and the general fear of the disease by those not infected with TB. It is also through the process of discussing the various themes that the narratives of the women are told.

INTRODUCING THE PARTICIPANTS

Bertha is an 85-year-old Métis woman and is the eldest participant.²³³ Bertha describes growing up in poverty and she only attained a grade four education. She recalls having to move countless times (both in urban and rural areas) so her father could find work as a labourer or woodcutter. The poverty her family experienced was compounded when her father died when she was 5 years of age.

Bertha's elder sister, Liz, was 19 years of age when she was diagnosed in 1946 with active TB. Bertha is unsure of how long Liz spent at Ninette Sanatorium but recalls it was probably a year or longer. Bertha describes Liz as a strong individual who never complained about her health.

Ben is the oldest person diagnosed with TB, being diagnosed around the age of 50. Ben's family, including his granddaughter Theresa, who I interviewed for this study, resided in a Métis

²³² The names of the towns where the participants reside are not mentioned so as to ensure their confidentiality.

²³³ Bertha was not for sure of exact dates and ages and the dates and ages mentioned are what she could recall.

community. Theresa said her grandfather had eleven children, of which at least two were young children when he was admitted to the Ninette Sanatorium in 1951. Ben's stay at the sanatorium lasted approximately nine months, at which time he left without the consent of the medical staff. Theresa also mentioned one of Ben's sister-in-laws, who from the same community was also admitted to the Ninette Sanatorium prior to her grandfather diagnosis. Theresa is an educated woman, holds a position of authority, and was the only participant who questioned if the diagnosis of TB was accurate in regard to her relative.

Marie is in her early 60s and has resided in the southwest region of Manitoba for the majority of her life. Her family was forcibly removed on two separate occasions from their lands by the federal government. It was in the road allowance community where her family settled after the first dispersal, where her cousin, Lorraine was diagnosed with TB. Marie estimated Lorraine was roughly 8 to 10 years old when she was sent to the sanatorium at Ninette for treatment. Marie also recalls Lorraine as not being the only individual from the community to be diagnosed with TB. She said an older woman was also sent to Ninette Sanatorium for TB treatment. Lorraine was sent to Ninette by train and only spent a couple of weeks there.²³⁴ Lorraine and her immediate family were treated differently after her diagnosis, such as children in the community being told by their parents not to play with Lorraine and her siblings.

Diane (the elder of the two) and Kelly are sisters whose mother, Sarah, was diagnosed with TB in 1952 at the age of 16. Sarah grew up in poverty and attended Indian residential school. Sarah was admitted at Ninette Sanatorium for approximately nine months and was the only individual of this study who experienced invasive treatment to treat her TB.²³⁵ Although Diane and Kelly are sisters, each provided different accounts of their mother's TB experience.

²³⁴ It generally takes patients with active TB two weeks of treatment before they are no longer infectious to others.

²³⁵ Sarah had a lung surgically removed whereas the relatives of the other participants received drug treatment.

Both sisters are university educated and work in the education field. Of all the participants in the study, Kelly appeared to be the most fearful of TB.

Each of the women in the study and their families are from a different area of the southwest region of Manitoba, but yet their backgrounds are relatively similar. This similarity can be directly linked to the impacts of colonialism on the Métis peoples. Consequences of colonialism mentioned by the participants include poverty, lack of education and the forcible removal from lands that resulted with individuals living in a road allowance community. As mentioned earlier, a number of things affect an individual's well-being such as education, employment, and environment and for those who are disadvantaged in these areas; they are more likely to contract diseases such as TB. Ultimately, the social and economic marginalization of the Métis, which resulted because of colonization, did contribute to TB among the Métis.

SANATORIUM EXPERIENCE

When participants were asked if their loved ones ever spoke about their sanatorium experience, most recalled their relative's accounts as being descriptions of very difficult and lonely experiences. This is consistent with the findings of Gibson and colleagues who found that loneliness was a common complaint by those who were admitted to TB sanatorium.²³⁶ For example, Diane recalls her mother telling her that while a patient at Ninette Sanatorium, "[she] was very lonely."²³⁷ Diane's younger sister, Kelly, further explains the loneliness her mother experienced,

... [she] just got it [TB] and was put in a sanatorium and was isolated from her family...I know my mom said it was the most loneliest time of her life, like she cried...they [the staff] got worried about her cause she was losing so much

²³⁶ Gibson et al "Socio-Cultural" 938.

²³⁷ "Diane," Interviewed by author. Digital voice recording. Manitoba, February 28, 2011.

weight, she was like ninety some pounds...she was going right down, she was so lonely, and she would cry, and she wouldn't eat.²³⁸

Bertha's sister, Liz, had a small child when she was admitted and as Bertha describes, "...yeah she was lonesome...we use to phone her...it's just she had to stay there...she was sad because she had to leave [her daughter and family]."²³⁹ When a person was sent to Ninette for treatment, it was unknown to the patient or family as to how long their stay would be.²⁴⁰ As will be discussed later in this chapter, many of the participants said their relatives did not receive visitors. The data indicates this did make their loneliness worse, because not only were all the participants' relatives from close knit families and communities, some had children.

The participants did seem to have heard more negative things about the sanatorium, but almost all could recall being told at least one positive thing about Ninette Sanatorium. As stated previously, my grandmother recalled the food being excellent. Another interviewee indicated that her mother "...made very close friends,"²⁴¹ while admitted. Marie recalls asking her cousin, Lorraine, about her stay at Ninette and remembers her saying she was treated well and even received candy from the staff.²⁴² Nobody had heard of the staff treating their relatives negatively because of being Métis and it appears from the stories that the staff seemed to be genuinely concerned for the patients' well-being; and, in the instance of my grandmother, the staff even went as far as collecting money so she could return home upon her discharge.

There are a number of reasons why patients may not have received visitors, which include poverty, distance, fear, and because patients may have been infectious and under

²³⁸ "Kelly," Interviewed by author. Digital voice recording. Manitoba, February 28, 2011.

²³⁹ "Bertha," Interviewed by author. Digital voice recording. Manitoba, December 12, 2010.

²⁴⁰ My grandmother use to say being in the sanatorium was worse than being in jail, because at least when you go to jail you are told how long you will be locked up.

²⁴¹ "Diane," Interviewed by author. Digital voice recording. Manitoba, February 28, 2011.

²⁴² "Marie," Interviewed by author. Digital voice recording. Manitoba, February 14, 2011.

quarantine. Poverty appears to be the most common reason why patients did not receive visitors. For example, Diane explained why she thought her mom did not get visitors, "... [they] were so poor that they couldn't go visit her or anything. She didn't have no money, so far away... Like you know, lots of them didn't have vehicles so how would they go there, so she spent most of that time there by herself."²⁴³ Ben resided the closest to Ninette, however even he did not receive many visitors as his granddaughter explains, "...dad went to see him...[but] mom said not too many went...because of the times, and grandma was home but their two youngest kids were just babies."²⁴⁴ Interestingly, only one participant indicated that their family was not allowed to go visit, which is probably due to the patient being under quarantine. Although, the reactions of the participants leads me to believe that even if the patients were not infectious and in quarantine, they would still not have received many visitors.

Since many of the patients were diagnosed when the disease was in the early years of being understood and effective treatments were unavailable, fear of infection was a significant concern. Theresa, discussing her grandmother's decision not to visit her grandfather, explains, "...she would have never gone there for fear that getting it...and giving it to her little kids."²⁴⁵ Kelly also recalls that even if her family did have money to go and visit, they probably would not have. It is evident that poverty was not the only reason why patients did not receive visitors, ignorance about TB transmission and fear were also common reasons relatives stayed away.

It is interesting that all of the participants recall their loved one experiencing loneliness while at the sanatorium, yet only one discussed the impact of the loneliness. Recent studies have found that those currently diagnosed with TB are more likely to experience anxiety and

²⁴³ "Diane," Interviewed by author. Digital voice recording. Manitoba, February 28, 2011.

²⁴⁴ "Theresa," Interviewed by author. Digital voice recording. Manitoba, February 22, 2011.

²⁴⁵ Ibid.

depression.²⁴⁶ In comparison to contemporary TB patients, the anxiety experienced by the TB patients discussed in this study, I believe, would have been greater because the dynamics of TB were not fully understood and treatments were often invasive, painful, and ineffective. The narratives of the participants provide a number of reasons as to why visitations did not occur such as poverty, distance, fear and quarantine. Although these reasons are valid and understandable, I believe the lack of family members and friends visiting was also a coping mechanism. It is possible that family members did not visit because they did not want to see their loved ones suffering physically, emotionally and mentally and because of fear of contagion. Two reasons lead me to this conclusion; first Kelly states that even if her family could afford to go and visit, they probably would not, and second, the treatment of my grandmother by her family when she was admitted to the sanatorium.²⁴⁷ Additional research is needed to explore this further, however I do believe family members and friends did not visit because they thought their relatives were going to perish from the disease and because of fears that they too would contract the disease if they were around their family members or other patients at the sanatorium.

Another interesting point is that the narratives passed along by the patients fail to recognize the impacts of the loneliness. For instance, when my grandmother discussed her time at the sanatorium she would always make a point of saying she did not receive many visits from her family but she did not discuss in detail how this affected her even though it did appear to upset her. There are two reasons patients may not have discussed how the loneliness affected

²⁴⁶ Ajit Shah, "A preliminary cross-national study of a possible relationship between elderly suicide rates and tuberculosis," *International Psychogeriatrics* 21.6 (2009), 1190; Georgios Moussas et al, "A comparative study of anxiety and depression in patients with bronchial asthma, chronic obstructive pulmonary disease and tuberculosis in a general hospital of chest disease," *Annals of General Psychiatry* 7.7 (2008), <http://www.biomedcentral.com/content/pdf/1744-859X-7-7.pdf>.

²⁴⁷ Many of my grandmother's items such as clothing and bedding were taken by her relatives while she was at the sanatorium. When she was released and returned home and questioned where her things were, her family said they thought she was going to die so they took them.

them. First, they may desire to avoid conflict with their family. Second, the patient may want to forget that their families did not visit during this difficult time.

CONTAGION MISCONCEPTIONS AND MISUNDERSTANDINGS

In order to protect oneself from an infectious disease, an individual must understand how the disease is spread. When participants were asked about how their relatives became infected, the answers varied. For example, Bertha and Marie were unsure of how their relatives contracted TB or why. The most surprising response came from Theresa, who was adamant that her grandfather did not actually have TB. She explains,

He said he didn't have TB...as I tell you this story you will see that maybe he didn't! Well...the more [my] mom talked the more I think grandpa might have been right, and I'll tell you why. The last two babies, and I thought about this and I wonder because...Doc ----- admitted him there [Ninette Sanatorium], and old Doc -----, you know from listening to all the older people, he was always trying to convince the half-breeds that they had enough children and they should do something about it. You know because 10 kids was too many, 12 kids was too many...I'm certain that when grandma had her last 2...because she had 11 and might have had lost some...He was probably telling her enough all ready because she must have been getting up there in age, she would have been already in her late 40s right when she had them...so I'm wondering if he [Doc -----] thought well if I put that old prick away for...new form of birth control. But anyway grandpa, mom said grandpa did make the comment more than once that...he didn't have [TB], he was convinced he didn't have TB. He wasn't coughing...nothing like that. And...to me, if he walked out of there after being there for nine months and never had another issue with his lungs in his whole life and he died in his 80s, I would tend to believe that he probably didn't. And he always said...I was put in there cause I was a breed...and you know grandpa had a very good relationship with a few people around town, like white people...and for him to say that...he must have really thought that right. And I don't know if he ever shared his reasons that didn't translate down. But he never had another issue with his lungs, *ever* [emphasis]. And he smoked his whole life! Right up til the day he died.²⁴⁸

Understanding how TB affects the body and how it is transmitted from one person to another, Theresa's grandfather's story raises questions about identity, racism, and the power physicians had during this period. It is possible that Theresa's grandfather did not have TB and it was a

²⁴⁸ "Theresa," Interviewed by author. Digital voice recording. Manitoba, February 22, 2011.

method to deter him from having more children with his wife. My grandmother was told on two separate occasions to have an abortion by doctors who said it would be too hard on her health to carry and deliver a baby. Although she did not take the doctor's advice in the case of her second child, within three months of the child being born she was again diagnosed with active TB and re-admitted to Ninette Sanatorium. This study cannot conclude that Métis women were told to abort pregnancies or Métis men were falsely diagnosed with TB as methods of birth control but perhaps further research in this area would be warranted.

There is no question as to whether or not Diane's mom had TB, but the way in which her mother is described as contracting the disease is surprising. Diane recalls both her mother and grandmother saying, "... she got it because when they would have their [women] monthly's...and you weren't dressed properly, especially in the winter time you would get TB... That's how she supposedly she got it, was she wasn't dressed properly in the winter time and when she had her monthly."²⁴⁹ Kelly, Diane's sister, also mentions this same event in casual conversation but when asked directly how her mother acquired TB she provides a similar explanation, but without reference to menstruation,

...cause they were very poor...My mom...like her dad died when she was what 5 or 8, I can't remember...But she was very young so my grandma had to go out and work...to make a living, and...I remember her telling me there were days when she had to walk to school and I guess in those days they had like cloth shoes, so...when she would get to school she could rinse [wringing motion with her hands] her shoes off...that's how...wet her shoes were. I remember her saying that.²⁵⁰

Similarities are evident within both of the sisters statements, one being poverty with a direct reference to inappropriate attire and the other being the fact their mother did not have adequate clothing. It is difficult to find a reason for why the sisters provide

²⁴⁹ "Diane," Interviewed by author. Digital voice recording. Manitoba, February 28, 2011.

²⁵⁰ "Kelly," Interviewed by author. Digital voice recording. Manitoba, February 28, 2011.

different explanations of how their mother was infected with TB, but it does illustrate how narratives can change as they are passed to others.

As a result of the continual evolution of TB contagion narratives a risk exists of new misconceptions and misunderstandings developing. For example, someone hearing Kelly explain how her mother contracted TB could conclude it was because she wore wet footwear. If this individual retells the story, the emphasis may be on the wet footwear and not the reason as to why her mother had improper shoes. One method that may stop misconceptions and misunderstandings associated to the modes of TB transmission is to introduce easily accessible public health education. For example, prior to learning about TB I thought it was possible that my grandmother acquired the disease by someone spitting in her food. However now that I understand how TB is spread, when I tell my grandmother's narrative I am sure to include the actual modes of TB transmission as well as what she believed.

FEAR

I posed two separate scenarios to each participant to try to determine if they were fearful about contracting TB. In the first scenario, each participant was to pretend that I was at their home and we were having tea. While drinking the tea I revealed that I had TB and continued to drink from their cups. Kelly stated, "I wouldn't even let you drink out of my cup."²⁵¹ The other interviewees were calmer and more relaxed and really did not display any great fears, although each did say they would bleach the cup after I left. The cup bleaching demonstrates the participants do not know how to stop the spread of TB germs since TB is an airborne illness and bleaching the cup would not provide protection.

²⁵¹ "Kelly," Interviewed by author. Digital voice recording. Manitoba, February 28, 2011.

The second scenario was similar to the first, except I had participants think about me visiting them in their homes and coughing and telling them I had been exposed to someone with active TB. Two participants were not concerned. Bertha, for example, did not think it was possible for her to catch TB since she had never gotten sick after being exposed to her sister who had TB. One participant went as far as to say, "...If we [her and I] were busy [at her place of work]... it may be the last thing from my mind but I bet you when I went home and started thinking about it, it would be 'oh shit'." ²⁵² So although she would show concern, TB would not enter her mind, even if I told her I was exposed and I was coughing. Another individual was more concerned I would give her H1N1, not TB.

Over the years I have had countless discussions with people, including the participants of this study, about TB transmission and the vast majority of people I have spoken to were not concerned about TB because they believed it is a historical disease that no longer exists. The participant who indicated her worry would be with H1N1 transmission raises an important point. This individual works on a First Nations reserve where recently someone has been diagnosed with TB. ²⁵³ She indicated that the reserve implemented a H1N1 prevention plan but that the reserve health clinic had little information about TB. Once a disease, such as TB, is no longer drawing public attention, individuals tend to think it is no longer a threat.

STIGMA

In order to understand stigma a definition is required. Link and Phelan explain stigma is what happens when, "...a person is identified by a label that sets that person apart and links the

²⁵² "Theresa," Interviewed by author. Digital voice recording. Manitoba, February 22, 2011.

²⁵³ Prior to interviewing the participant I was speaking to her and some of her coworkers and they all told me about a member of the community being diagnosed with TB in recent years.

person to undesirable stereotypes that result in unfair treatment and discrimination,”²⁵⁴ and “...significantly discredits an individual in the eyes of others.”²⁵⁵ A number of things contribute to stigma including fear, ignorance, and lack of education.

None of the participants used the term stigma to describe how their relatives were treated, but it is apparent by their stories that those infected with TB were treated differently because of their diagnosis. For example, Marie said her cousin and another woman, who was also sent to Ninette for treatment, were treated different by the community members after receiving their TB diagnosis. When asking her about how the community responded, she sat quietly sipping her tea, and then with a sad tone she began to speak,

The reason it made such a big impact on me was we couldn't play with her. Like our parents wouldn't allow us to play with her [cousin]... Yeah the other lady she was there for years and then... my cousin came back but we still weren't allowed to play with her for a long time afterwards... I think... if I remember correctly we went there [somewhere in the community] and... we were playing in these... old cars and then my dad come got us... he said not until we know for sure, when he come got us... I don't remember seeing any other kids around there. So pretty well everybody in that community shunned that family I think pretty well until they were certain she didn't have it.²⁵⁶

It is evident the community was fearful of the disease, not only were the children told to stay away from Lorraine, the community took it a step further,

If she used their same dish ... [or] stuff like that... we weren't allowed to share anything with that little girl, like we weren't allowed to play with her to begin with and when we did, like you know my parents found out they came and get us... If she [Lorraine] had gum in her hand, she gave it to us, we weren't allowed to take it, stuff like that. Her clothes, even her clothes I remember... they were burnt, like they burnt her clothes you know!²⁵⁷

²⁵⁴ Sushil C. Baral, Deepak K. Karki, and James N. Newell. "Causes of Stigma and Discrimination Associated with Tuberculosis in Nepal: A Qualitative Study." *BMC Public Health* 7, no. 211 (August 2007): 2.

²⁵⁵ Peter Aggleton, Kate Wood, Anne Malcolm, and Richard Parker. *HIV - Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes* (Geneva, Switzerland: UNAIDS, 2005): 7.

²⁵⁶ "Marie," Interviewed by author. Digital voice recording. Manitoba, February 14, 2011.

²⁵⁷ Ibid.

The members of Lorraine's community were tested for TB, but Marie was adamant that public health education was not offered.

The remaining participants did not say if their relatives were treated differently. Theresa recalls that her community, "...[did not make] a big deal out of it at all...it wasn't like...nobody really said don't come visit us, there was none of that."²⁵⁸ Expanding upon this she said, the community, "...lack[ed]...understanding about how severe it [TB] could be,"²⁵⁹ which is most likely the reason why this community did not become frightened. Diane's community used her mother's TB experience as a way to prevent future cases of TB,

I know it was...known in the community that it's a very bad disease to get so yeah they talked about it, you know, and after that then they started saying that you better make sure your kids and...everybody's dressed properly in the winter...so they sent caution out to the community that after she got it, then I think she was used like ... [an] example...right? So...they did talk about it but in a way where it was like...prevention for other families not to get the TB.²⁶⁰

The members of the community who used Sarah's TB experience to educate others about the disease may in fact have been putting people at risk, because failing to dress for the conditions is not a mode of transmission.

It seems the communities that were tested, such as in the case of Lorraine's, were more fearful of TB in comparison to communities that were not tested, such as Sarah's. Theresa explains that the community where her grandfather was from, "... [did not] make a big deal out of it at all...it didn't sound to me like there was a fear in the community."²⁶¹ Lorraine was unable to recall exactly what her community was told about TB, but it is plausible they were told of the worst case scenario, death, which increased the community's fear of TB. Whereas, the

²⁵⁸ "Theresa," Interviewed by author. Digital voice recording. Manitoba, February 22, 2011.

²⁵⁹ Ibid.

²⁶⁰ "Diane," Interviewed by author. Digital voice recording. Manitoba, February 28, 2011.

²⁶¹ "Theresa," Interviewed by author. Digital voice recording. Manitoba, February 22, 2011.

lack of education provided to Theresa's grandfather's community may have actually put people at undue risk of contracting the disease.

Bertha recollects that her sister Liz was not stigmatized by her family because of her TB diagnosis but was unsure how she was treated outside of the family. During my interview with Bertha, I had asked if at the time of Liz's diagnosis if she had heard much about the disease in the media or if she had heard of TB prior to her sister acquiring it. Her response was, "...we didn't even know [of] Ninette, where they kept *them* [emphasis]."²⁶² Although she referred to the Ninette Sanatorium patients as 'them' she did not seem to classify her sister as one of 'them', because she nonchalantly stated Liz was only going to Ninette Sanatorium to get the fresh air she need, glossing over the fact that Liz was going away to receive treatment for a life threatening illness. Bertha also mentioned that her eldest daughter, who was young at the time of Liz's diagnosis, had bad lungs and experienced bouts of pneumonia and pleurisy. She did say the child was taken to the doctor numerous times for respiratory problems but insisted she was never tested for TB. I asked if she had told the physician that her sister had TB and she replied almost angrily, "no, nobody would tell him!"²⁶³ Similar to my grandmother's experience who kept her TB status a secret to avoid being discriminated against, Bertha did the same, possibly jeopardizing the health of her child.

As discussed, stigma develops from fear and ignorance and results with individuals being treated differently. The data of this study suggest that if the participants were to be in contact with a person diagnosed with TB, they would treat them differently. For example, Kelly would not allow a person with TB to drink from one of her cups. Kelly's limited knowledge about TB has manifested into a fear of TB, which results in her displaying a discriminatory behaviour

²⁶² "Bertha," Interviewed by author. Digital voice recording. Manitoba, December 12, 2010.

²⁶³ Ibid.

based upon misconceptions of contagion. This is similar to the stigma my cousin displayed towards my grandmother, not allowing her to hold her great grandchild. The failure to provide public health education to TB patients, their families and communities in the early to mid 20th century, in combination with the contemporary lack of public health messaging about the disease, has perpetuated false narratives of TB transmission that contribute to stigma and fear.

EDUCATION

Today, when a person is diagnosed with active TB, those who have been in close contact with the person are tested for TB, but this has not always been the case. For example, Liz suffered from TB symptoms for months before she was diagnosed and sent to the sanatorium. During this time she was frequently in contact with her family and the public. However, when asking Bertha about whether her family was required to get tested, she said, "...they [healthcare workers] never asked us to."²⁶⁴ Theresa also said that nobody in her family, or the small close-knit Métis community she is from, was tested. Only Marie's community was tested, and although tested, no education was provided.

Three of the participants did not believe TB is a current health problem in Canada. Theresa and Marie had both read articles pertaining to how TB is problematic in northern Manitoba, which is how they knew TB was still an ongoing problem. I felt Theresa was the most knowledgeable about TB, but she still lacked an understanding of how to protect herself if exposed to an infected individual. Also, she mentioned her daughter, a healthcare worker, had been accidentally poked by a dirty syringe from an infected TB patient, which of course led to a series of tests. She explains,

...one of my daughters was a healthcare aide and...was looking after... [a] patient...in...[an] isolation ward. And she went in and was cleaning up the bed

²⁶⁴ "Bertha," Interviewed by author. Digital voice recording. Manitoba, December 12, 2010.

and somebody had left a needle and she had poked herself with this needle and he had TB...apparently. And they supposedly, I think she said they do 2 or 3 checks of you after that. They did the first one and then she never went back for the second one. And then she started having this naggly {sic} little cough and again I went into panic mode. So TB still makes me panic!²⁶⁵

Although this situation caused panic within Theresa, her daughter a healthcare worker seemed to disregard how serious this situation could have become. It also raises the question as to why the employer did not ensure Theresa's daughter completed all the required tests to ensure, not her own safety, but also the safety of those around her.

In addition to the belief that TB is no longer a problem, none of the participants had ever seen educational material or advertising pertaining to the disease. It became apparent how little the participants knew about the disease when I presented the question, "How do you think you get TB?" Two participants indicated they did not know how the disease was transmitted from one person to another, while one believed it was a virus. Theresa was somewhat correct when stating, "...from somebody who is infected," but then she continued to say she did not know.

Bertha could only provide a guess as to how her sister and other people would acquire TB,

...just bad luck I guess cause nobody else was sick and really she [Liz] wasn't sick either she just said her lungs were just sore all the time...just like a bad cold...I don't think [I could]...catch it from you, I don't know how...I don't think it was catching because they sent her out the sanatorium just because of her lungs, she needed lots of air...that's the way you got it, just like cancer, you get better...[Liz] never complained, as far as we know, it was just like cancer, cause cancer you get better or you die. And that's...well how would we know...we would have to be tested, and none of us ever got tested for that...we aren't scared, we aren't scared of it...none of us are {sic} ever scared of it.²⁶⁶

Bertha also told me that she would not be concerned about contracting TB from me

because she had never became ill after being in close contact with her sister when she

was diagnosed with TB.

²⁶⁵ "Theresa," Interviewed by author. Digital voice recording. Manitoba, February 28, 2011.

²⁶⁶ "Bertha," Interviewed by author. Digital voice recording. Manitoba, December 12, 2010.

As previously stated the participants' relatives were diagnosed with TB from as early as 1946 until late 1950s. Not only was public health education not offered during this time, it continues to be absent. Posing the question, if any participants had seen information such as pamphlets on the topic of TB Theresa said, "No, no I haven't...and I look at all [of them], just this morning [the same day as the interview] I was sitting there [doctor's office] waiting for [my daughter] looking at a whole range of them, and you do all the time, and I have never yet seen one on TB."²⁶⁷ Diane and Kelly do recall being tested for TB because it is mandatory for their employment. This is the only time (1985) Diane recalls seeing information about the disease.

In January of 2011, while in Brandon, I went to eight pharmacies, four walk-in medical clinics and the hospital and found no visible public health information about TB. I also asked staff at these facilities if pamphlets were available to those who requested them, all answered no. However, for diseases such as cancer, HIV/AIDS, and arthritis, pamphlets were visibly displayed at each establishment. Educational material about TB appears to be non-existent within the city of Brandon and while I have not systematically looked in other contexts, I have been able to find information, although limited, in other cities (Edmonton, Saskatoon, Vancouver) across Canada. This is worrisome because not only do Aboriginal peoples represent 10% of Brandon's population there are a number of Métis communities and reserves nearby.²⁶⁸ If education about TB does not make its way into Brandon and surrounding communities, it is likely people will not know how to protect themselves if they are exposed to an infected source.

²⁶⁷ "Theresa," Interviewed by author. Digital voice recording. Manitoba, February 22, 2011.

²⁶⁸ Brandon Regional Health Authority. *Community Health Assessment 2009* (Brandon, MB: Brandon Regional Health Authority, 2009): 1-6.

The failure to provide adequate TB public health messaging has enabled the misconceptions in the narratives to continue to be passed along inter-generationally. For instance, my grandmother's narrative has affected four generations of my family and most likely will continue to do so until the narrative is altered to include the facts about TB, such as how it is spread and treated.²⁶⁹ As said previously, narratives do continually evolve so if public health messaging about TB is provided it would help to address the misconceptions within lay narratives.

STOPPING THE SPREAD

The ongoing failures on behalf of the Canadian healthcare system to provide TB public education has resulted in TB being thought of as a disease of history and no longer a threat to Canadians. Each participant in this study expressed a need for education as a vital component to stopping the spread of disease and to counteract misconceptions and fears associated with TB. Diane, when asked what she thinks healthcare workers could do, states,

...there's lots they could do, yeah like that would be number one right...a prevention plan. Just like they did for H1N1, like you know make sure everybody's aware this is how you catch it, and if you are showing signs of this make sure [you] go and see a doctor and request a TB test. You know prevent the spread right...There's lots they can do!²⁷⁰

Marie explains why education about TB is important,

...how they would stop that [TB is to] maybe have more education out there like educational material like at the dentist, or doctor, whatever... yeah have it up, have it there so people are more aware of what it is so there's no stigma attached to it right. I know even when...I talk with a few people and we talk about TB they don't know very much about it, I know I don't...but even if people had to know,

²⁶⁹ When I pass along my narratives about my grandmother's experience with TB I do include the actual modes of transmission, diagnosis, and treatment. However, not everyone in my family understands the basics of the disease and I have heard them pass along incorrect information.

²⁷⁰ "Diane," Interviewed by author. Digital voice recording. Manitoba, February 28, 2011.

supposing your family is diagnosed with TB even...make...the other members in the family, and...extended family aware of what it is, how it can be treated and even just basic information so they know it's not something you can catch from drinking from the same cup.../... you know how hard it is for someone to come back [referring to being released from a sanatorium or hospital and returning to the community] and, it would be kind of, shunned...that's because of what's attached to it.²⁷¹

Interestingly, when Theresa was explaining what she thought the healthcare system should do to eradicate TB, she was genuinely concerned about TB continuing to be a problem,

...just a little bit of information...would go a long ways...like if you know [if] someone has a persistent cough and you know and they have been to your home...just take a bit of precaution...or it can be caught as easy as two people sitting there chatting and one sneezing in somebody's face...just give people the facts and let them [learn]...cause if you've never heard of it and to be honest with you before I thought that about [name withheld] or started seeing that in the paper I bet I hadn't thought of TB since somebody casually mentioned it at a family gathering, you know our grandpa was in the sanatorium, right...you don't think of it cause it really doesn't affect your life and you don't realize even walking here in our hospital that the person laying in that room could have TB.²⁷²

The eldest of the participants has the least amount of knowledge about TB.

Although her sister had been in and out of the sanatorium a number of times, Bertha has never received any education about the disease. This was clearly evident in her statement, "I don't know how [you get TB], what could you do about it... [education] would help cause nobody knows...nobody ever knows how you get it."²⁷³ It is well over sixty years since Bertha's sister was diagnosed with TB, however Bertha still does not understand the basics of TB transmission and treatment.

All the participants indicate that education would be beneficial to not only preventing future infections but also to inform people the disease still exists. Marie went

²⁷¹ "Marie," Interviewed by author. Digital voice recording. Manitoba, February 14, 2011.

²⁷² "Theresa," Interviewed by author. Digital voice recording. Manitoba, February 22, 2011.

²⁷³ "Bertha," Interviewed by author. Digital voice recording. Manitoba, December 12, 2010.

beyond just discussing prevention and argues that education would also be useful to reduce stigma. She explains that if basic education is provided it could help address the misconceptions that result with TB patients being stigmatized, as well as it would help educate those who have never heard of the disease. Even though none of the participants fully understood the basics of TB, they all recognize the importance of providing education as a means to control the disease.

SUMMARY

Numerous commonalities exist among narratives presented in this study including the backgrounds of the participants; the patient's experiences; misconceptions and misunderstandings; fear; stigma; and the general lack of knowledge about TB. Also evident within the stories are the impacts of colonization. For example, poverty was an issue that affected all of the Métis individuals discussed in this study, and as previously mentioned, colonization led to the social and economical marginalization of the Métis. For some, their poverty was extreme, such as in the case of Bertha who said her sister could not afford to feed herself or her child, and Sarah's family who could not afford to provide adequate clothing. The poverty experienced by these Métis families also meant that when their loved ones were admitted to the Ninette Sanatorium, they could not go and visit regularly, if at all.

Oral narratives have and continue to be used by Métis people to pass along information from one generation to the next; however, problems are evident when examining the intergenerational narratives about TB. The stories provided by the participants, in combination with the lack of public health messaging, have allowed misconceptions and misunderstandings about TB to be passed from one generation to the next. This, in turn, seems to have resulted in the participants having a fear of the disease, but not recognition that individuals today could

possibly have TB. This is worrisome because the participants do not know how to reduce their chances of acquiring TB if in contact with an infected source.

TB stigma can be directly linked to fear and the lack of knowledge associated to the disease. The participants did not use the term stigma when discussing how their relatives with TB were treated, but the narratives reveal those with the disease were stigmatized because of their TB status. The stigma experienced by the patients includes having their clothing burnt and reduced contact with members of their family and community. One participant was so concerned about stigma that she kept her sister's TB status a secret, putting the health of her daughter in jeopardy. Stigma was also evident when trying to find participants for this study. Numerous people who fit the study requirements would speak to me but when I asked if they would participate in the study they either said no or indicated that nobody in their family had TB.

The stigma attached to TB can be linked to the historical treatment of patients, families and communities. Marie was the only individual that recalled her community being tested for TB but was adamant that education was not provided. The families and communities of Ben, Liz and my grandmother were not tested, nor were they provided any education.²⁷⁴ It is interesting TB testing was not done in the Métis community where Ben resided considering that just prior to his admittance to the Ninette Sanatorium, his sister-in-law was diagnosed with active TB.²⁷⁵ Failure to provide education to the TB patients of this study, as well as their families and communities, has shaped perceptions of TB and left the participants of this study vulnerable to contracting TB if exposed.

²⁷⁴ Kelly and Diane mother had TB prior to both of them being born.

²⁷⁵ I have also spoken to three other individuals from this community who either had TB or had family members with TB.

CHAPTER 7 RECOMMENDATIONS

The evidence found in this study concludes that intergenerational tuberculosis narratives do affect how the Métis participants in this study perceive TB. In order to address the contemporary issues of stigma and misconceptions relating to TB, public health education about the disease must be made available. Other issues requiring attention include the economic and social marginalization of the Métis that resulted from colonization. Each of these issues needs to be addressed in order to prevent TB from becoming more problematic in the southwest region of Manitoba.

EDUCATION

Throughout the southwest region of Manitoba, educational material and advertising on the subject of TB is nearly non-existent.²⁷⁶ The Communicable Disease Control Branch of Manitoba [CDCB] suggests the preventative measures required to stop the transmission of TB are education and awareness. The report, *Tuberculosis (TB) Protocol*, states, “Educate the public, particularly populations at increased risk of exposure to, infection with, or development of TB, about: Signs and symptoms of active TB disease; Advantages of early identification and treatment of LTBI [latent TB infection].”²⁷⁷ Although these aspects are important, there are a number of issues with what CDCB encompasses under the umbrella of education. For example, they fail to mention the risk factors associated with TB, nor do they discuss the means by which a person can protect himself or herself from contracting the disease. It seems as though the CDCB primary concern is educating those already affected by TB and neglecting those who are not.

²⁷⁶ Vast quantities of educational material do exist online if a person has access to a computer.

²⁷⁷ Latent TB infection [LTBI] is when a person has been exposed and infected by TB but is not infectious to others. Manitoba Health, Communicable Disease Control Branch. *Tuberculosis (TB) Protocol*, 13.

Development of educational material specifically aimed at the Métis population, as well as other Aboriginal groups, is necessary. CDCB indicates people should contact the Canadian Lung Association [CLA] for additional educational material pertaining to TB.²⁷⁸ Information about TB is provided in over twenty languages on the CLA website, however no information is offered in an Aboriginal language.

Upon questioning the CLA as to why information was not available in Aboriginal languages²⁷⁹ I was directed to look at the Health Canada website. When comparing the literature

Information for Aboriginal Peoples



Health Canada, "TB is Curable," http://www.hc-sc.gc.ca/fniah-spnia/alt_formats/pdfpubs/disease-maladies/tuberculosis/tb_booklet_fn_eng.pdf (accessed August 04, 2011).

Information for General Society

INFORMATION ABOUT TUBERCULOSIS

1. What is tuberculosis?

- Tuberculosis is an infectious disease caused by a germ called the *tubercle bacillus*.
- Anyone can be infected with the TB germ.
- The TB germ enters the body as you breathe and usually settles in the lungs. From there it can spread to other parts of the body.
- When you are first infected with the TB germ, you do not usually get sick, but the germ remains in your body in an inactive state.
- The germ can become active at any time in your life. Not all people with inactive infection will get active TB. Most often this happens when you are older, or if you get another disease that lowers your ability to fight infections.
- When the germ becomes active, it causes the disease known as tuberculosis or TB.
- There is medicine to give to people who have inactive infection to prevent the disease from becoming active.

2. How is TB spread?

- When a person with active TB breathes out, for example by coughing, sneezing or talking, the TB germs go from their lungs into the air.
- People become infected by breathing in the air that is carrying the TB germ.
- Only people who have the active form of TB of the lungs can spread the infection.
- People who have inactive infection cannot pass TB to another person.
- TB is most often spread to people who spend a lot of time with a person with active TB, especially those who live in the same house.

Canadian Lung Association, "Information about Tuberculosis: English," http://www.lung.ca/_resources/tub_english.pdf (accessed August 04, 2011).

²⁷⁸ Communicable Disease Control Branch. *Tuberculosis (TB) Protocol*, 13.

²⁷⁹ Health Canada only provides TB material in Inuktitut; no other Aboriginal languages are available.

of the CDCB and the CLA, one must question as to why the literature aimed at Aboriginal peoples is childish, cartoonish and incomplete. For example, the information for the general population provides the basis about what TB is and the most common mode of transmission. In comparison, the material for Aboriginal peoples fails to define TB, any modes of transmission, or list any of the behaviours that increase susceptibility. Also, the Aboriginal material downplays the significance of the disease, making it seem like TB is a simple disease to cure, which is not always the case.

As previously mentioned, the lack of providing education to the patients discussed in this study, in combination with the ongoing absence of public health messaging has resulted in lay narratives contributing to misconceptions and misunderstandings associated to the disease. Therefore, agencies such as Health Canada and the Canadian Lung Association do need to design and circulate education materials that are understandable²⁸⁰, concise, and easily assessable.

REDUCING STIGMA AND MISCONCEPTIONS BY ADDRESSING FEAR

The interviews collected during this research reveal that the stigma and misconceptions linked to TB are due to a lack of education and awareness about TB. Each participant had some fear of TB and as a number of scholars argue, fear does lead to increased stigma towards TB patients.²⁸¹ Marie's interview provided a clear picture of the fear her community held towards TB; children were not to share candy with a young patient even though she was no longer infectious and her clothing was burnt. If this community had received education, they would

²⁸⁰ Medical terminology should be avoided.

²⁸¹ Emmanuel Atsu Dodor and Shona Kelly, "We are Afraid of them': Attitudes and Behaviours of Community Members towards Tuberculosis in Ghana and Implications for TB Control," *Psychology, Health & Medicine* 14, no. 2 (March 2009): 172; Baral, Karki and Newell, "Causes of Stigma and Discrimination," 8; Clif van der Oest, et al., "Talking about TB: Multicultural Diversity and Tuberculosis Services in Waikato, New Zealand," *The New Zealand Medical Journal* 118, no. 1216 (June 3, 2005), 3.

have known that taking a candy from someone or being in contact with their clothing poses little if any risk to contracting the disease.

TB is a disease inundated by two types of misconceptions. The first stems from stigma and the second is rooted in history. The most common misunderstandings about TB involves ideas about how infection occurs. For instance, interviewees believed you could catch TB by a common cold getting worse whereas another indicated women could catch it by not dressing properly in winter when menstruating. In the case of my grandmother, she attributed her TB to an infected person spitting on her food. Although each of these beliefs is highly improbable to cause transmission, the biggest misconception shared by the participants is that TB is no longer a threat. Underlying the second type of misconception is the historical treatment of TB patients. Many believe that if one becomes infected they will be placed in a sanatorium for treatment while others believe the disease still results in death.²⁸² Reducing stigma and addressing misconceptions by utilizing education should aide in the prevention of future cases of TB. Failure to do so will not only allow the stigma and misconceptions to continue to play a role in rates of TB transmission, but also as a number of scholars argue, failing to address the negativity in regard to TB will most likely result in patients choosing not to seek or adhere to medical treatment.²⁸³

ALTERING EXISTING NARRATIVES

The evidence corresponds with the importance of oral tradition among Métis peoples. All of the participants appear to fully believe the TB narratives they have been told by their

²⁸² Some individuals are placed in quarantine until they are no longer infectious. This typically takes two to three weeks with the proper medication regimen.

²⁸³ Karki Baral and Newell. "Causes of Stigma and Discrimination," 2; Javaid Ahmed Khan, et al, "Knowledge, Attitude and Misconceptions regarding Tuberculosis in Pakistani Patients," J Pak Med Assoc, Vol 56, no. 5 (May 2006), 211-13.

loved ones. However, in doing so a problem develops because TB narratives are a recollection of a personal experience or observation, and can mislead people to engage in activities that increase risks of contracting TB. For example, the majority of the narratives discussed a means of transmission that is highly improbable or impossible, yet participants did not appear to question what they had been told. It is obvious that because education was not provided to patients, their families or communities in the past, incorrect information has continued to be passed from one generation to the next.

If education were provided, eventually the information would become incorporated into the existing narratives. For example, when I tell my grandmother's story I always make a point of including the misconception about how she thought she acquired the disease and I also make sure to mention the actual modes of TB transmission to the listener. The misconceptions discussed in this study should remain within the existing narratives because they demonstrate how the patients, their loved ones and communities tried to make sense of the disease when it was not fully understood by the medical system. Introducing education into existing narratives in combination with maintaining the existing misconceptions, allows the words and thoughts of historical TB patients to be preserved while providing contemporary listeners factual and relevant information about the disease.

DECOLONIZATION AS A MEANS OF PREVENTION

When examining why TB has remained problematic among the Métis and other Aboriginal peoples it must be questioned as to what role colonialism has played and continues to play in the transmission of the disease. As previously mentioned, colonialism was an attempt to control every aspect of Aboriginal people's lives including health, culture, traditions, education, spirituality, economics, and language. When comparing the risk factors of TB, which according

to the Public Health Agency of Canada are: close contact with an infected source, overcrowded living conditions, being in a correctional facility, prior TB infection, HIV/AIDS, weak immune system, underlying medical conditions (diabetes), poverty, residing in a community with cases of active TB, and homelessness²⁸⁴ to how colonization has impacted the lives of Métis peoples, it becomes obvious that colonization and present day manifestations of structural racism experienced by Métis contributes to high rates of TB amongst this population.

The racist colonial practices imposed on Métis peoples have ultimately resulted in them being disadvantaged in comparison to the dominant society in areas of health, education, and employment. This places them at higher risk for infectious diseases, including TB. For example, Métis youth in Brandon are less likely to complete high school and are more apt to live in homes receiving social assistance.²⁸⁵ Factors such as overcrowding, homelessness, incarceration and exposure to TB are much higher among this population than the general public. For Métis people experiencing poverty and marginalization, the risk factors associated with TB are part of daily life.

To eliminate TB from the Métis population it is necessary to begin the process of decolonization, which is "...a process where a colonized people reclaim their traditional culture, redefine themselves as a people and reassert their distinct identity."²⁸⁶ Ultimately, for the decolonization process to be achieved in the area of TB, input from Métis peoples is essential. For example, those working in the field of TB control must work in partnership with Métis communities and organizations to design and implement culturally relevant programs, which incorporate the Métis worldviews. Although this will not eliminate TB, it will provide Métis

²⁸⁴ Public Health Agency of Canada. "Tuberculosis Fact Sheets."; Canadian Lung Association. "Tuberculosis."

²⁸⁵ Martens et al, *Profile of Métis Health*, 601-02

²⁸⁶ Bill Mussell, "Cultural Pathways for Decolonization," <http://heretohelp.bc.ca/publications/aboriginal-people/bck/2> (accessed August 20, 2011).

individuals a means to protect themselves from contracting the disease and hopefully reduce rates of TB until other aspects of decolonization can occur (i.e. improvements in housing, employment, education).

RECOGNITION OF MÉTIS PEOPLES

In order to improve the overall health status of Métis people, problematic areas must first be determined and then solutions found. Currently there are no means by which to track cases of TB among Métis peoples in Manitoba. For instance, the form filled out by physicians to report new cases and relapses of TB does not include specific information about the Métis. The Communicable Disease Control Investigation Form²⁸⁷ provides a check box area for individuals to enter ethnicity or race but under the heading “Aboriginal” it only provides check boxes for First Nations and Inuit. This error on part of Manitoba Health provides incorrect information in regard to the disease burden among the Métis population.

Métis are one of the three recognized Aboriginal groups in Canada under the Constitution. However, there is a discrepancy in regard to the health benefits each receives. For instance, First Nations and Inuit people’s health benefits are funded by the federal government whereas the various provincial and territorial governments pay for Métis health. Although each recognized group is to receive similar health care, there is significantly more data collected about First Nations and Inuit than about Métis health and health care usage.

One method which could be implemented to track the health and health care usage of the Métis population is for the federal government to take responsibility for health services to all Constitutionally recognized Aboriginal peoples. In doing so, it would allow for methods of recording to occur among the three groups and it would assist in the collection of data in regards

²⁸⁷ Manitoba Health, “Communicable Disease Control Investigation Form,” <http://www.manitoba.ca/health/publicheath/cdc/protocol/form2.pdf> (accessed June 29, 2011)

to where the healthcare system is lacking for Canada's Aboriginal peoples including what programs may be most beneficial and effective. Another method which could eliminate confusion about the health status of Métis people is to drop the term "Aboriginal" when it comes to health related literature. For example, the majority of government agencies such as Health Canada, Public Health Agency of Canada, and Correctional Services of Canada use the term Aboriginal when publishing data, but the majority of the data is First Nations specific. In addition, by recognizing Métis peoples and their distinct needs in regard to health will allow this population to become visible and have their needs more appropriately addressed. However, if they remain forgotten or are made invisible, present problems will continue to manifest and possibly grow.

CHAPTER 8 CONCLUSION

This study concludes that historical and contemporary lay TB narratives of Métis peoples, such as those given by the five Métis participants in this study, continue to influence the public's understanding of TB rates, transmission, prevention and treatment. The oral accounts that each participant heard from their relative contain a number of misconceptions about TB. These misconceptions, in conjunction with the lack of public health messaging available has resulted in people being unsure as to how they can protect themselves against TB. Not only have lay narratives left the participants vulnerable, but also their children and grandchildren because the stories continued to be passed down from one generation to the next.

Lay TB narratives can contribute to elevated rates of TB among the Métis, however it is the lingering consequences of colonialism, such as poverty, that elevate the known risk factors of TB. Although the participants did not directly discuss colonialism, the links to colonization were present in each account of TB. For example, all of the participants' relatives who were diagnosed with TB were living in a state of poverty at the time of the diagnosis, four families had been removed from their traditional homelands, and one had attended residential school. The ongoing effects of colonialism continues to keep Métis peoples disadvantaged in areas of health, education and income and failure by provincial and federal governments to rectify the problems, keeps the Métis marginalized and disadvantaged, and increases the likelihood that TB will remain a serious health problem among this population.

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APPENDIX A

INTERVIEW QUESTIONS

- So it was your [mom, sister, grandfather, cousin] that had TB?
- When he or she was diagnosed do you know where they living?
- Do you what year it was when they had TB?
- Did he/she ever say how he/she got it?
- Do you know where he/she had it? For example, the lungs or did she have it in another part of her body?
- Did he/she have to go to a sanatorium for treatment? If so, which one?
- Do you know how long he/she was there?
- Did he/she talk about the sanatorium at all?
- Did he/she ever say they were treated differently at the sanatorium because of being Métis?
- Do you think he/she was treated any different because he/she was Métis?
- I have heard number stories about Métis patients escaping from the sanatorium, one of them being my grandma. Do you know if your [relative] was discharged or did he/she just leave?
- Did you get to visit him/her at the San? Do you know if anyone else in your family visited him/her? If not, why?
- Do you know how your family reacted to the diagnosis? What about the community?
- Was he/she the only one in your family to get TB?
- Why do you think your mom got it and say not (her husband, you, etc)?
- Do you know if your family or community was tested?
- Did his/her TB ever come back?

- Have you heard any of the Old People²⁸⁸ in your community talk about TB?
- Some people believe you get TB because they were bad or because of bad medicine. What do you think? Have you ever heard anyone say this?
- Do you think TB is still an issue?
- How do you think a person gets TB?
- If I was coughing a lot would you be worried at all? What if I said I might have been exposed to TB? Say I drank from one of your cups, what would you do with it?
- Have you ever seen pamphlets or heard about TB say at the doctor's office, in the newspaper, on the news?
- Do you think there is anything healthcare workers can do to stop the spread of TB?
- Is there anything you would like to add?

²⁸⁸ Certain Métis communities refer to their respected elders as 'Old People'

APPENDIX B CONSENT FORM

Title: *Understanding Narratives of Illness and Contagion as a Strategy to Prevent Tuberculosis among Métis in Southern Manitoba*

Principal Investigator: Velvet Maud

Telephone: (204) 725-3835

You are invited to be part of a research project being conducted by Velvet Maud, a graduate student in the Department of Native Studies at the University of Saskatchewan. The purpose of this project is to find out how family and community narratives influence the way Métis peoples view the transmission of tuberculosis, what they do to try and prevent it, and their choices in seeking healthcare.

What You Will Be Asked to Do?

If you decide to participate in this study you will be asked to participate in one personal interview about your experience with tuberculosis. Questions will include: when you were diagnosed, did you spend time in a sanatorium, how do you think tuberculosis is passed from one person to another, etc. The interview will take approximately one to three hours in duration. Your participation in this study is entirely voluntary.

Risks

- There is a possibility you may become uncomfortable answering the questions.
- Except for your time and inconvenience, there are no foreseeable risks to you by participating in this study.

Benefits

- You will receive a gift for your participation (a mug and a box of tea).
- Your input will be used to inform national and provincial Métis organizations and healthcare decision-makers provide better tuberculosis services and programs for Métis people.

Confidentiality

Your interview will be voice recorded or video recorded (participants choice) to ensure accuracy and be transcribed. You have the right to review the transcript and to remove anything you so desire. Your name will not be on any of the documents and nobody will have access to the transcripts, voice recordings or video recordings. Prior to using any direct quotes, I will contact you and review the information with you. You may also request a copy of your transcript or video recording.

The information gathered will be used to complete my graduate thesis. In addition, a report will be made and given to the Manitoba Métis Federation-Southwest Region, other provincial Métis organizations, healthcare agencies and providers outlining the research findings and policy recommendations.

The information may be published, used in presentations, or as teaching material. Again, your name will not be mentioned in any material. A unique number or pseudonym will be used to protect your identity and a master list will be created to allow the researcher to link the names and numbers or pseudonyms. Although every measure will be taken to ensure confidentiality a possibility exists that you may be identifiable based on what you said during the interview.

Consent forms and a list of participants will be kept separate from other data, such as the transcripts and recordings, and kept within a safe at my place of residence. All remaining data will be kept my personal computer and password protected. Upon completion of my graduate thesis, all materials will be stored within a locked filing cabinet in the office of Dr. Caroline Tait. All data and files will be appropriately destroyed after a minimum of five years, unless you agree to have your interview(s) donated to the Archives of Manitoba to ensure the survival of your story. The master list will be destroyed when it is no longer required.

Transcript Release Protocol

As a participant in this study I understand I have the choice to donate my interview(s) to the Archives of Manitoba, and this is entirely voluntary. I realize that by agreeing to donate the material to the Archives of Manitoba that my *identity will be revealed*. I acknowledge the interview will be donated no sooner than three years after the original interview and I have the right to revoke this authorization any time prior to the donation of the recorded interview.

Voluntary

Participation is voluntary. If you choose to take part in this study, you may stop at any time during the study without penalty. You have the right to skip any questions you do not wish to answer as well as you can ask that the recording device be turned off. In the event that you wish to drop out of the study you will be allowed to keep the gift. If you drop out of the study, none of the information you have provided will be used and it will be destroyed three months after the interview in case you change your mind.

Contact Information

If you have any questions about this study at anytime, please contact me at (204) 725-3835 or by email at metis_333@hotmail.com. Also, you may contact my supervisor: Dr. Caroline Tait at (306) 966-6956 or caroline.tait@usask.ca.

If you have any questions about your rights as a participant in this study, please contact the Ethics Office at the University of Saskatchewan: (306) 966-2084 (collect).

If you wish to find out the results of this study, please contact Velvet Maud at (204) 725-3835 or via email at metis_333@hotmail.com or Dr. Caroline Tait (306) 966-6956 or caroline.tait@usask.ca.

Voluntary Consent and Subject Withdrawal

I have read and understand the above information. I have been told what my participation will involve and about any possible risks. I have been provided the opportunity to ask questions in regard to the study and have received acceptable answers. I hereby consent to participate in the study, *Understanding Narratives of Illness and Contagion as a Strategy to Prevent Tuberculosis among Métis in Southern Manitoba*. I also understand that I have the right, without penalty to withdraw from the study at any time. A copy of this consent form will be provided to me.

Participant's name – please print

Participant's Signature

Date

Signature of Primary Investigator (Velvet Maud)

- | | | |
|--|------------------------------|-----------------------------|
| 1. Do you agree to have your interviews donated to the Archives of Manitoba? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 2. Do you want a copy of your transcript? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 3. Do you want to review a copy of your transcript? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

If you answered yes to either question #2 or #3, please provide contact information:

Address: _____

City/Town: _____ Postal Code: _____

APPENDIX C
CONSENT FORM: WAIVER OF CONFIDENTIALITY

Title: *Understanding Narratives of Illness and Contagion as a Strategy to Prevent Tuberculosis among Métis in Southern Manitoba*

Principal Investigator: Velvet Maud

Telephone: (204) 725-3835

You are invited to be part of a research project being conducted by Velvet Maud, a graduate student in the Department of Native Studies at the University of Saskatchewan.

The purpose of this project is to find out how family and community narratives influence the way Métis peoples view the transmission of tuberculosis, what they do to try and prevent it, and their choices in seeking healthcare.

To provide the reader with understanding of how the disease can affect, not only the patient, but family members I want to use the narratives you have passed along to me about your mother's experience with tuberculosis as well as the stories about how your mother's tuberculosis experience affect your life. Both your name and the name of your deceased relatives will be used within my thesis; however no names of living relatives will be recorded.

All narratives that I have heard by you, as well as your mother, will be written as accurately as I can remember them. Upon completing the writing of the stories, I will forward you a copy to review. You have the right to review the narratives and remove anything you so desire. No formal interview will take place and prior to using any quotes; I will contact you and review the information with you.

Only given names will be used within my thesis of yourself and your deceased relatives. The information gathered will be used to complete my graduate thesis. In addition, a report will be made and given to the Manitoba Métis Federation-Southwest Region, other provincial Métis organizations, healthcare agencies and providers outlining the research findings and policy recommendations.

The information may be published, used in presentations, or as teaching material. Again, your given name may be used in this material. All consent forms and a list of participants will be kept separate from other data, such as transcripts and recordings, and kept within a safe place of residence. All remaining data will be kept my personal computer and password protected. Upon completion of my graduate thesis, all materials will be stored within a locked filing cabinet in the office of Dr. Caroline Tait. All data and files will be appropriately destroyed after a minimum of five years. The master list will be destroyed when it is no longer required.

What You Will Be Asked to Do?

If you decide to participate in this study there are no requirements you must fulfill and your participation in this study is entirely voluntary.

Risks

- There is a possibility you may become uncomfortable reading the stories. The stories will include what your mother (Gertie) told me about her illness experience as well as your personal narratives of her disease, and how it has affected your life.
- There are no foreseeable risks to you by participating in this study.

Benefits

Your input will be used to inform national and provincial Métis organizations and healthcare decision-makers provide better tuberculosis services and programs for Métis people.

Consent

As a participant in this study, I fully understand that my *identity will be revealed*. I have read and understand the above information. I have been told what my participation will involve and about any possible risks. I have been provided the opportunity to ask questions in regard to the study and have received acceptable answers. I hereby consent to participate in the study, *Understanding Narratives of Illness and Contagion as a Strategy to Prevent Tuberculosis among Métis in Southern Manitoba*. I also understand that I have the right, without penalty to withdraw from the study at any time. A copy of this consent form will be provided to me.

Voluntary

Participation is voluntary. If you choose to take part in this study, you may stop at any time during the study without penalty. You have the right to skip any questions you do not wish to answer as well as you can ask that the recording device be turned off. If you drop out of the study, none of the information you have provided will be used. All data pertaining to you will be destroyed three months after you drop out of the study in case you change your mind.

Contact Information

If you have any questions about this study at anytime, please contact me at (204) 725-3835 or by email at metis_333@hotmail.com. Also, you may contact my supervisor: Dr. Caroline Tait at (306) 966-6956 or caroline.tait@usask.ca.

If you have any questions about your rights as a participant in this study, please contact the Ethics Office at the University of Saskatchewan: (306) 966-2084 (collect).

If you wish to find out the results of this study, please contact Velvet Maud at (204) 725-3835 or via email at metis_333@hotmail.com or Dr. Caroline Tait (306) 966-6956 or caroline.tait@usask.ca.

Voluntary Consent and Subject Withdrawal

I have read and understand the above information. I have been told what my participation will involve and about any possible risks. I am fully aware that my given name and the names of

some of my deceased relatives will be used. I have been provided the opportunity to ask questions in regard to the study and have received acceptable answers. I hereby consent to participate in the study as well as to let the research use my given name in her thesis entitled, *Understanding Narratives of Illness and Contagion as a Strategy to Prevent Tuberculosis among Métis in Southern Manitoba*. I also understand that I have the right, without penalty to withdraw from the study at any time. A copy of this consent form will be provided to me.

Participant's name – please print

Participant's Signature

Date

Signature of Primary Investigator (Velvet Maud)